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## Adding Life to the Adolescent's Years, Not Simply Years to the Adolescent's Life: The Integration of the Individualized Care Planning & Coordination Model and a Statutory Fallback Provision

Kimberly Gordy

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NOTE

**Adding Life to the Adolescent's Years, Not Simply Years to the Adolescent's Life: The Integration of the Individualized Care Planning & Coordination Model and a Statutory Fallback Provision**

**Kimberly Gordy\***

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ADDING LIFE TO THE ADOLESCENT'S YEARS

INTRODUCTION

Yesterday Tyler had friends over playing x-box and rock band. They were laughing, joking, and the biggest question on their minds was will tomorrow be a snow day. Today Tyler is surrounded by a team of nurses and doctors injecting 5 different toxic chemotherapy drugs directly into his heart . . . . By 5:00 the side effects had already begun. I am continually amazed at how smoothly Tyler makes the transition between these two worlds. It is a sign of great strength and maturity. He does a far better job than I do . . . . It is an amazing and humbling thing when your greatest life lesson is taught to you by your own teenage son.<sup>1</sup>

The above passage was written by the parent of seventeen-year-old Tyler Alfriend, a patient with stage IV Burkitt's Lymphoma and Leukemia. Tyler's ability to balance these opposing worlds exemplifies the dignity and maturity exhibited by so many teenage patients coping with critical illness. For these young adults, their teen years are not the jaunty bridge between childhood and adulthood, a time during which teens discover their world without regard for mature considerations. Instead, the reality of their illness often results in fulminant entry into adulthood. While coping with the realization that they may not reach their next birthday, these teens also assume the responsibility of assuaging the grief of their families. Although there is never a good time in one's life to face a life-threatening illness, experts have recognized that the adolescent years may be among the hardest.<sup>2</sup>

Many physicians admit that critically ill adolescent patients are in a relative "no man's land."<sup>3</sup> In many ways, adolescent patients are like pediatric patients, needing both emotional and physical support from their families. However, these patients are not children, and the maturity demonstrated by many teens warrants the medical decision-making autonomy given to adult patients. Take the case of Michael Miller, who at age sixteen was diagnosed with cancer so advanced that his treatment included fifty-one weeks of chemotherapy, radiation, and surgery.<sup>4</sup> In the wake of his diagnosis and his parent's admitted hopelessness, Michael's physician stated that Michael showed maturity when he "calmed his parents' fears and helped them focus on the task ahead."<sup>5</sup>

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1. Kyle Alfriend, *Round 5*, TYLER ALFRIEND—FIGHT TO WIN! A TEENAGERS VICTORY AGAINST BURKITT'S LYMPHOMA/LEUKEMIA (Mar. 10, 2008, 21:30 EST), <http://tyleralfriend.blogspot.com/2008/03/round-5.html>.

2. Cf. Roni Caryn Rabin, *In Cancer Fight, Teenagers Don't Fit In*, N.Y. TIMES, Mar. 16, 2010, at D1, available at <http://www.nytimes.com/2010/03/16/health/16canc.html> (discussing the difficulties facing teenage cancer patients).

3. See, e.g., *id.*; see also Rachel Hollis & Sue Morgan, *The Adolescent with Cancer at the Edge of No-Man's Land*, 2 LANCET ONCOLOGY 43, 43 (2001).

4. Elizabeth Jane Walker, *Roll Model: With Help from St. Jude, Michael Miller Transcends Obstacles in His Way*, PROMISE, Autumn 2009, at 6, available at <http://www.stjude.org/SJFile/Autumn09Prom.pdf>.

5. *Id.* at 8.

In a groundbreaking study conducted at St. Jude Children's Research Hospital, researchers produced data supporting what Michael Miller's physician already knew—that critically ill adolescents do have the ability to negotiate the complex medical decision-making process.”<sup>6</sup> The adolescent study's participants both understood the consequences of their decisions and were capable of participating in a decision process involving risks to themselves and to others.<sup>7</sup>

In spite of their evident developmental maturity, American adolescents lack the legal standing to apply these skills. As a result, the final months of their lives are often fraught with conflicts over decision-making autonomy, with the most severe conflicts necessitating judicial resolution. Although practitioners are aware of the “no man's land” that is adolescent critical illness, the available scholarship does not adequately address this significant bioethical conflict. As advances in medicine superannuate the current decision-making framework, this void in scholarship has never been more apparent. The current medical literature is limited by the assumption that a legal intervention is unnecessary so long as a trusting relationship between the doctor, patient, and family is maintained.<sup>8</sup> In reality, few physicians are equipped to manage a teen's end-of-life care, and the family often feels abandoned by the care team in the patient's final weeks.<sup>9</sup> Equally insufficient, the available law review literature focuses primarily on the public health rights of teens, such as a minor's right to seek an abortion. Unfortunately, the standards and arguments for these issues do not translate to a teen facing cancer or muscular dystrophy. Although a limited number of pieces offer an analysis of the common law mature minor doctrine,<sup>10</sup> these articles do not consider whether legal intervention is truly in the patient's best interest. Nor does the current literature offer a process designed to elucidate the adolescent patient's wishes without increasing conflicts arising from family disagreements, poor communication, and disjointed clinical care.<sup>11</sup> This Note overcomes these deficiencies by presenting a formalized process that integrates the expertise of the medical community with the resources of the legal system.

The proposed process is dependent upon a careful assessment of both the adolescent's personal wishes and the family's dynamics, followed by a negotiation process and the development of a comprehensive plan. This Note

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6. See Pamela S. Hinds et al., *End-of-Life Care Preferences of Pediatric Patients with Cancer*, 23 J. CLINICAL ONCOLOGY 9146, 9153 (2005).

7. *Id.* at 9146.

8. COMM. ON PALLIATIVE AND END-OF-LIFE CARE FOR CHILDREN AND THEIR FAMILIES, WHEN CHILDREN DIE: IMPROVING PALLIATIVE AND END-OF-LIFE CARE FOR CHILDREN AND THEIR FAMILIES 327 (Marilyn J. Field & Richard E. Behrman eds., 2003) [hereinafter *WHEN CHILDREN DIE*] (noting that promoting trust is a strategy for handling conflicts).

9. See *id.* at 328, 334.

10. See, e.g., Christophe Lemmens, *End-of-Life Decisions and Minors: Do Minors Have the Right To Refuse Life Preserving Medical Treatment? A Comparative Study*, 28 MED. & L. 479 (2009).

11. See *id.* at 293 (noting that cultural misunderstandings, poor communication, and deficient clinical care are avoidable conflicts).

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recommends conducting an individualized assessment of each adolescent patient to ensure that he or she receives the appropriate level of autonomy needed to feel at peace with his or her condition, family, and care team.<sup>12</sup> By initiating communications long before the patient's imminent death, those conflicts which most often require judicial intervention will be identified by the medical team and family prior to the point of crisis. Legal intervention becomes the final option only if no other agreement can be reached.

This Note aims first to prove the benefits of individualized patient care, and second, to recommend a model to better implement this heightened level of patient-centered medicine. Part II argues that an adolescent's intrinsic assets are a more accurate tool for assessing a critically ill teen's maturity, and explains that critically ill minors are often better equipped to make well-conceived medical decisions than many healthy adults. Part III enumerates the limitations of a parent's decision-making capacity when faced with decisions about their critically ill child and the use of life-sustaining medical treatment (LSMT).<sup>13</sup> Part IV asserts that the current legal health care exceptions for minors are inappropriate when applied to critically ill adolescents. Finally, this Note advocates an individualized approach to adolescent medical decision making and recommends use of the Individualized Care Planning and Coordination Model (ICPC). The ICPC model, developed at St. Jude Children's Research Hospital, is a comprehensive yet compassionate tri-phase approach to advance care planning.<sup>14</sup> This Note both builds on the ICPC model and recommends that state legislatures adopt a statutory fallback provision to guide adolescent medical decision making.

## I. A PINCH OF THIS, A SPRINKLE OF THAT: WHAT ARE ADOLESCENTS MADE OF?

Because one must initially understand adolescent development before appreciating adolescent autonomy, this Part discusses how development relates to

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12. See generally Javier R. Kane & Joanne Hilden, *Tools To Aid Decision Making in the Care of Pediatric Patients with Cancer*, in AMERICAN SOCIETY OF CLINICAL ONCOLOGY EDUCATIONAL BOOK 188-89 (2007) (offering a thorough discussion of the importance of individualized care).

13. For the purposes of this Note, LSMT encompasses any treatment that could possibly delay a patient's imminent death in the foreseeable future. This includes well-known treatments such as ventilator support, cardio pulmonary resuscitation, antibiotics, artificial nutrition and hydration, and dialysis. This Note also discusses participation in a clinical trial, including the use of experimental chemotherapy for terminal cancer patients. Like LSMT, the treatment protocol in a Phase I clinical trial will not cure the patient. However, trial participation differs because such treatment may actually shorten the patient's lifespan. The purpose of a Phase I clinical trial is to evaluate a new drug or treatment course to determine the maximum tolerable dose, any toxicities, and the metabolism and elimination of the drug (pharmacokinetics). See Mason C. Bond & Sheila Pritchard, *Understanding Clinical Trials in Childhood Cancer*, 11 PEDIATRIC CHILD HEALTH 148, 148-49 (2006). Eligible participants have typically received, but not responded to the standard treatment protocol. The curative efficacy of the treatment is not evaluated at this stage. See *id.*

14. See Kane & Hilden, *supra* note 12, at 190. See St. Jude Children's Research Hospital, <http://www.stjude.org> (last visited Oct. 7, 2010), for general information on the hospital.

adolescent maturity. Applying proven theories of developmental psychology, the following Part redefines the manner in which an adolescent's maturity and decision-making ability should be evaluated. By eliminating the disadvantages of previous capacity assessments, the forthcoming discussion of the use of intrinsic assets to gauge maturity creates a more accurate assessment of a critically ill teen's maturity level. Next, these developmental assets are considered in the context of the critically ill minor, explaining why many critically ill minors are better equipped to make a well-conceived medical decision than are many healthy adults.

### *A. Redefining the Developmental Evaluation of Intrinsic Assets*

Society tends to measure an individual's development by the achievement of external milestones. For example, seventy-two percent of Americans surveyed consider the completion of school to be the milestone signifying the end of adolescence and the beginning of adulthood.<sup>15</sup> After graduation, Americans were more likely to rank full time employment and beginning a family to be milestones signifying maturity.<sup>16</sup> However, for the three thousand teens that die annually from chronic illnesses, these achievements are either impractical or impossible.<sup>17</sup> While these external milestones may signify adulthood, they are neither necessary nor sufficient for emotional and intellectual maturity. Rather, external milestones are a byproduct of an adolescent's intrinsic development—in other words, the ability to both reason as an adult and interact successfully with a peer group.

When evaluating maturity, a terminally ill teen's achievements should never be compared to those of their healthy peers. Teens should be assessed intrinsically to determine if they are functioning as successful young adults, albeit within the confines of their illness. The essential question is: but for the limitations of the illness, has the teen demonstrated the attainment of independence and appropriate social cognition necessary to prove an attainment of maturity?<sup>18</sup>

#### *1. Attainment of Independence: The Piaget Theory*

As adolescents progress through their teen years, developmentalists expect a

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15. Paul Arshagouni, "But I'm an Adult Now . . . Sort of": Adolescent Consent in Health Care Decision-Making and the Adolescent Brain, 9 J. HEALTH CARE L. & POL'Y 315, 317 (2006); Tom W. Smith, *Coming of Age in Twenty-First Century America: Public Attitudes Towards the Importance and Timing of Transitions to Adulthood*, 29 AGEING INT'L 136, 138 (2004).

16. See Smith, *supra* note 15, at 138-139.

17. David R. Freyer, *Care of the Dying Adolescent: Special Considerations*, 113 PEDIATRICS 381, 381 (2004).

18. *Id.* at 381-82 (noting that life-threatening illness alters the normal physical and psychological development of an otherwise normal adolescent).

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gradual separation from the family unit. An emotionally healthy adolescent adopts a future-oriented view of the world, marked equally by a sense of individuality and a concern for others.<sup>19</sup> According to the Piagetian theory of development, this enhanced thought-process occurs because the teen has reached the formal operations stage, or the final stage of development.<sup>20</sup> Unlike younger children, teenagers have the capacity to think about the future, the abstract, and the hypothetical. Having this capacity signifies that they have reached the Piaget stage of formal operations."<sup>21</sup> As the ability to reason is a component of maturity, it is important to understand how the use of formal operations allows a teen, unlike a child, to consider many different alternatives at once. The following is an example of the difference in the reasoning ability of a child compared to that of an adolescent: A person is presented with five jars, each containing a colorless liquid. He or she is told that combining the liquids from three particular jars will produce a color, whereas using the liquid from either of the two remaining jars will not produce a color. A color can be produced, but he or she is not shown which combination produces this effect. Children at the concrete-operational stage typically try to solve this problem by combining liquids two at a time, but after combining all pairs, or possibly trying to mix all five liquids together, their search for the workable combination usually stops. An adolescent at the formal-operational stage, on the other hand, will explore all possible solutions, systematically testing all possible combinations of two and three liquids until a color is produced.<sup>22</sup> Just as adolescents can explore all possible solutions to make the color change, they are able to weigh all proposed treatment options and the consequences of selecting or rejecting the various choices presented by the physician. Having reached formal operations, the teen fosters an inner moral compass and utilizes deductive reasoning skills on a daily basis to make decisions.<sup>23</sup> Teens able to reason in this manner will have the ability to choose their path after a weighted evaluation. This new perspective allows the teen to foresee a life apart from his or her parents. Despite the egocentrism associated with this stage, this expression of autonomy is essential for establishing self-

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19. *Id.* at 382.

20. DOROTHY G. SINGER & TRACEY A. REVENSON, A PIAGET PRIMER: HOW A CHILD THINKS 26 (1996). The Piagetian theory of development has been applied by psychologists for decades and is a well-accepted measure of development. The four stages are (1) Sensory Motor, (2) Preoperational, (3) Operation, and (4) Formal. Although the Piagetian theories have been expanded and modernized over time, the core concepts remain in use by developmental psychologists. *Id.* at 20-26.

21. *Id.* at 26. Cf. Marc H. Bornstein et al., *Human Behavior*, in *ENCYCLOPAEDIA BRITANNICA ONLINE*, <http://www.britannica.com/EBchecked/topic/275332/human-behaviour> (last visited Oct. 7, 2010) (explaining that Jean Piaget's fourth and final stage of formal operations is when an adolescent operates as an adult).

22. See Bornstein, *supra* note 21 ("[A]ccording to Piaget, children organize and adapt their experiences with objects into increasingly sophisticated cognitive models that enable them to deal with future situations in more effective ways.").

23. See SINGER & REVENSON, *supra* note 20, at 26.



confidence and integrity.<sup>24</sup>

## 2. Social Cognition and a Healthy Self-Image

The development of social cognition is concomitant with a healthy self-image.<sup>25</sup> This process takes place over the course of three sub-stages across the span of adolescence.<sup>26</sup> During early adolescence, ages ten to fourteen, the overall cognitive focus shifts one's attachment from parents to peers.<sup>27</sup> During middle adolescence, ages fifteen to seventeen, a teen's social development requires the consolidation of self-image and feelings of both achievement and power.<sup>28</sup> Middle adolescents also begin experimenting with ideas, friendships, and the way they present themselves to society.<sup>29</sup> This psychosocial process is referred to as role diffusion versus identity.<sup>30</sup> Role diffusion describes the process by which teens "try on" different personalities until they find their true self.<sup>31</sup> A physically healthy adolescent may experiment with styles and different peer groups in an effort to gain acceptance.<sup>32</sup> A teen's identity is composed of his or her self-concept, task behavior, and perceived peer acceptance.<sup>33</sup> Although this perception may or may not be accurate, projection is a common phenomenon during the adolescent period. Younger teens typically interpret the actions and attitudes of their peers as a reflection of their own self-worth and self-image.<sup>34</sup> During the period of late adolescence, teens enjoy a greater sense of security in who they are and in their relationships with others.<sup>35</sup> The teen fosters an "appreciation for meaningful relationships" and is acutely attuned to the dynamics within peer and family units.<sup>36</sup> This new appreciation gives them the

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24. *See id.* ("[I]n the formal operations stage, adolescents now ha[ve] the necessary 'mental tools' for living life.").

25. Cognition is defined as: "The mental activities such as thinking, reasoning, remembering, perceiving. The process by which the seemingly random information presented by the environmental and social stimuli around a person is organized into meaningful units for memory and ultimate action." *Id.* at 127-28.

26. Freyer, *supra* note 17, at 381.

27. *Id.*

28. *Id.*

29. *See id.* at 382 (noting that teens are able to consolidate these social processes because they have developed advanced abstract reasoning).

30. *Cf.* DONNA L. WONG, WONG & WHALEY'S CLINICAL MANUAL OF PEDIATRIC NURSING 271 (4th ed. 1996) (identifying the stage of adolescent patient development as one of identity versus role diffusion).

31. *See* Jennifer Wagaman, *Psychosocial Development of Adolescents: Two Stages of Development as Described by Erik Erikson*, SUITE101.COM, Dec. 11, 2008, [http://parentingteens.suite101.com/article.cfm/psychosocial\\_development\\_of\\_adolescents](http://parentingteens.suite101.com/article.cfm/psychosocial_development_of_adolescents).

32. *Id.*

33. *Id.* Task behavior refers to what activities people choose to become involved in. *See id.*

34. *See id.*

35. *See* Freyer, *supra* note 17, at 381-82.

36. *Id.* (explaining that late adolescence "is characterized by increase sense of comfort,

opportunity to become socially adept and independent.

*B. The Modern Day Secret Garden: The Critically Ill Adolescent's Opportunity to Attain Independence and Social Skills*

In *The Secret Garden*, "sickly" teen Colin Craven achieves normal emotional development after having had the opportunity to interact with peers and take on responsibility.<sup>37</sup> His "coming of age" depends upon his achieving normal social relationships and ending the isolation imposed on him by his caregivers. Like this classic character's, a critically ill teen's coming of age is not dependent upon his or her physical health, but is instead influenced by the strength and normalcy of his or her social relationships.<sup>38</sup> When critically ill teens are not exposed to the interactions necessary to facilitate this developmental growth, it is possible that these teens will reach developmental stages later than their peers.<sup>39</sup>

For the critically ill teen, the desire for independence constantly conflicts with the reality of needing constant care from family and medical professionals.<sup>40</sup> The prolonged hospital stays and frequent outpatient treatments can prevent a teen from attending school, participating in extracurricular activities, or forming romantic relationships.<sup>41</sup> Ultimately, overprotective parents and isolation from peers prevent teens from experiencing the necessary internal conflict of identity versus role diffusion.<sup>42</sup> These limitations support the belief that critically ill teens are less mature than their healthy counterparts.

Fortunately, psychosocial impairment does not have to be a side effect of critical illness. A recent study of teens receiving treatment for cancer in the first remission found that the patients were mostly well-adjusted when compared to their healthy peers.<sup>43</sup> Adolescent patients that receive age-appropriate social support are best enabled to follow as typical a developmental trajectory as

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awareness of others, and appreciation for meaningful relationships").

37. See generally Frances Hodgson Burnett, *THE SECRET GARDEN* (1998) (1911).

38. See Freyer, *supra* note 17, at 381-82, 386-87.

39. See Danai Papadatou & Judith M. Stillion, *Suffer the Children: An Examination of Psychosocial Issues in Children and Adolescents with Terminal Illness*, 46 AM. BEHAV. SCIENTIST 299, 299-315 (2002). ("Seriously ill children may find that either because of disease or treatment side effects . . . peers may begin to shun them . . . . [T]hey may not be able to take part in normal childhood activities . . . .").

40. Freyer, *supra* note 17, at 382.

41. See *id.*

42. See WONG, *supra* note 30, at 271 (mentioning the internal conflicts that accompany an adolescent patient struggling with identity versus role diffusion); Sarah J. Sinclair, *Involvement of Adolescents in Decision Making for Heart Transplants*, 34 AM. J. MATERNAL/CHILD NURSING 276, 278, 280 (2009) (noting the importance of positive peer influences and the need for open communication).

43. Freyer, *supra* note 17, at 382 (citing R.B. Noll et al., *Social, Emotional, and Behavioral Functioning of Children with Cancer*, 103 PEDIATRICS 71, 71-78 (1999)).

possible.<sup>44</sup>

Psychosocial support is often provided by in-hospital intervention programs, such as Child Life Services, or targeted experiences, including those provided by specialized camps for teens with chronic illnesses.<sup>45</sup> Child Life Services are available in most major pediatric centers. This service serves both inpatients and outpatients, and often directs the in-hospital school program and oversees the emotional transition from hospital to home.<sup>46</sup> All child life specialists have earned a minimum bachelor's degree and are trained to provide psychosocial support to pediatric and adolescent patients and their families. The child life specialist facilitates the learning process by which the teen becomes informed about the condition and prognosis, and customizes the information for the teen's level of development.<sup>47</sup> For example, older teens are encouraged to talk and learn about the illness through support groups and scientific literature.<sup>48</sup> The activities require the use of formal operations, and therefore challenge the teen both emotionally and intellectually.<sup>49</sup> To aid in the development of identity, the child life specialist will often require the patient to find a hobby, such as watercolor painting or learning a foreign language.<sup>50</sup> If the teen was previously involved in an activity, the care team would insist that the teen continue nurturing the established talent.<sup>51</sup>

It is imperative that hospitalized adolescents participate in both the adolescent life program and the in-hospital school program in order to develop normal social cognition.<sup>52</sup> These programs create opportunities for teens to form friendships with other patients, mirroring the peer interaction they would receive were they able to attend school. The child life team is also instrumental in helping patients preserve out-of-hospital friendships.<sup>53</sup> Because many teens are

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44. *Id.* at 386-87 (describing how social support and guidance can help adolescent patients experience meaningful events and relationships that may otherwise have been foreclosed to them).

45. Alyssa Quintero, *MDA Summer Camp*, QUEST, Mar./Apr. 2005, [http://www.mda.org/publications/Quest/q122golden\\_memories.html](http://www.mda.org/publications/Quest/q122golden_memories.html); Association of Hole in the Wall Camps, <http://www.holeinthewallcamps.org/Page.aspx?pid=332> (last visited Oct. 7, 2010).

46. *See generally* Child Life Council, the Child Life Profession, <http://www.childlife.org/The%20Child%20Life%20Profession> (last visited Oct. 7, 2010).

47. *Id.* ("All certified Child Life Specialists must complete a supervised 480-hour clinical internship, pass a national examination, and adhere to a minimum standard for continued professional development in order to maintain their certification.").

48. *See id.*

49. *See* SINGER & REVENSON, *supra* note 20, at 26-27, 127 (explaining formal operations).

50. Children's Hosp. & Research Ctr. Oakland, Child Life Services, [http://www.childrenshospitaloakland.org/child\\_life/life\\_overview.asp](http://www.childrenshospitaloakland.org/child_life/life_overview.asp) (last visited Nov. 2, 2010).

51. *Id.* *See* Christy Price Rabetoy, *The Benefits of a School Teacher vs. a Child Life Specialist Serving Pediatric Patients on Dialysis*, 35 NEPHROLOGY NURSING J. 399, 399-401 (2008).

52. *See generally* Child Life Council & Comm. on Hosp. Care, *Policy Statement: Child Life Services*, 118 PEDIATRICS 1757, 1757-61 (2006) (providing a thorough description of child and adolescent life services and advocating that these services should be considered an essential component of quality pediatric health care).

53. *See* Rabetoy, *supra* note 51, at 399-401.

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apprehensive about peers visiting them in the hospital, the team provides "cool" activities, such as Wii games to help the adolescent bridge the gap between patient and peer.<sup>54</sup>

Camps designed for patients facing illness are especially important for developing age-appropriate maturity, as they facilitate the formation of their intrinsic developmental assets.<sup>55</sup> Participants experience the same activities that their healthy peers engage in during summer camp and have the opportunity to form meaningful relationships without the fear of peer rejection.<sup>56</sup> The most important component, however, is independence.<sup>57</sup> Teens are separated from their parents, accountable for their own enjoyment, and must independently perform as many daily tasks as physically possible.<sup>58</sup>

Each of the programs described above provides opportunities for increased self-awareness and reliance. The incorporation of problem solving and self-evaluation in these specialized activities forces ill teenagers to employ formal operations in the same manner that their healthy peers apply formal operations in school or extra-curricular activities.<sup>59</sup> While the physical development of a critically ill adolescent may be altered by illness, emotional maturity can be achieved with appropriate interventions.<sup>60</sup>

### *C. The Importance of a Workable Concept of Death*

As children move into adolescence, their beliefs about death evolve from perceiving it as temporary and reversible to understanding death to be universal, unalterable, and permanent.<sup>61</sup> A workable concept of death, an important developmental step, is perhaps the most important asset needed for mature medical decision making.<sup>62</sup> The realization and understanding of a workable concept of death is determined by an individual's personal encounters with

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54. See Georgetown Pediatrics, Child Life Program, <http://www.georgetownuniversityhospital.org/body.cfm?id=557459> (last visited Jan. 4, 2010); see generally Child Life Council & Comm. on Hosp. Care, *supra* note 52, at 1757-61; Beth Israel Medical Center's Child Life Program Receives Support From the Startlight Starbright Children's Foundation, [http://www.wehealny.org/pressroom/starlight\\_starbright\\_intern.pdf](http://www.wehealny.org/pressroom/starlight_starbright_intern.pdf) (last visited Nov. 2, 2010).

55. Alyssa Quintero, *MDA Summer Camp*, QUEST, Mar./Apr. 2005, [http://www.mda.org/publications/Quest/q122golden\\_memories.html](http://www.mda.org/publications/Quest/q122golden_memories.html) ("Camp is still so important because it gives the campers a sense of learning in terms of how to share and how to have patience. It's a great chance to learn about what life is really like.").

56. *Id.*

57. Association of Hole in the Wall Camps, <http://www.holeinthewallcamps.org/Page.aspx?pid=332> (last visited Nov. 7, 2009).

58. *Id.*

59. See generally Child Life Council & Comm. on Hosp. Care, *supra* note 52, at 1757-61 (describing the intellectual and social value of Child Life services).

60. Freyer, *supra* note 17, at 382 (noting that the physical changes associate with puberty are often absent or delayed as a result of treatment or disease).

61. *Id.*

62. *Id.*

death.<sup>63</sup> A healthy adolescent's experience with death is typically the demise of a grandparent or pet. Although this can be a profound loss, exposure to the dying process is often limited and thus death remains largely external in nature.<sup>64</sup>

Unlike their healthy peers, adolescents with a life-limiting illness will have developed an astute understanding of their own impending death as "the cumulative result of personal experiences with serious illness and medical treatment."<sup>65</sup> These teens have also experienced the death of friends, and thus fully understand the consequences of disease, treatment, and grief.<sup>66</sup> Death is understood not only in terms of its personal significance but also in the way it will affect their friends and family.<sup>67</sup>

## II. THE FAMILY UNIT: UNDERSTANDING AND ACCEPTING THE PROGNOSIS

Why would I want a tube in my throat? I saw other patients like that—I don't want that. I wouldn't be able to talk with my family or hold my Mom's hand. That is not living.

*15-year-old young woman with acute lymphoblastic leukemia*<sup>68</sup>

We were kind of really happy that they had chemotherapy, something else that we could try.

*15-year-old young woman with a solid tumor*<sup>69</sup>

We decided not to go with chemo because I don't want to be sick the rest of my days, and it's not like it is going to cure me, so I just said, 'we'll go home and take it from there.'

*15-year-old young woman with acute lymphoblastic leukemia*<sup>70</sup>

Pediatric palliative care is a uniquely challenging field and can be emotionally draining for the care team itself as well as the family.<sup>71</sup> The burden

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63. *Id.*

64. *Id.*

65. *Id.*

66. *See id.* (explaining that understanding death requires actual experiences with death, whereas many children are insulated from the dying process and only witness death in movies and video games).

67. *Id.* (highlighting the importance of a critically ill patient's understanding of death).

68. Hinds et al., *supra* note 6, at 9150.

69. *Id.*

70. *Id.*

71. Tammy I. Kang, David Munson & Jeffrey C. Klick, Preface, *Pediatric Palliative Care*, 54 PEDIATRIC CLINICS N. AM. xv, xv-xvi (2007). Palliative care is defined as "the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social, and spiritual problems is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families." *Id.* at xv.

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of facilitating medical decision making often falls on the pediatric palliative care team, and this team must be both sensitive to the patient's wishes and cognizant of the family dynamics in order to provide the patient with a positive "experience of life despite the sadness of an untimely death."<sup>72</sup> This Part explains the difficulties faced by the care team, parents, and the patient when there is no longer a realistic hope for a cure. Section A examines the reasons behind the parents' choice to continue treatment with a curative intent and the challenges providers face in effectively communicating prognosis. Section B explains why the patient's acceptance of prognosis is a gestalt entity, comprising both intuition and past medical experiences.

To ensure a thorough understanding of the prognosis, the palliative team has three responsibilities to a patient following a dying trajectory.<sup>73</sup> First, the patient and family must receive accurate and timely information on the diagnosis, prognosis, and treatment options.<sup>74</sup> Second, when the initial or subsequent treatments fail, the team must provide information about the burdens and benefits of the remaining treatment options and prognosis.<sup>75</sup> Third, when further life-prolonging interventions fail, the care team must then support the patient through the dying phase of the illness, as well as ensure that the family has support during and after the patient's death.<sup>76</sup>

When an adolescent has an illness that is life-limiting by nature or that has progressed beyond the possibility of a cure, the condition will take on one of two trajectories.<sup>77</sup> Understanding which trajectory the course of illness will take impacts the amount of preparation time the patient and family will have and underscores the importance of tailoring care to the specific course of illness.<sup>78</sup>

The first trajectory represents patients who have a fatal progressive condition, such as muscular dystrophy or cystic fibrosis.<sup>79</sup> These types of conditions are characterized by periods of slowly deteriorating health status, interrupted by potentially fatal medical crises.<sup>80</sup> The patient repeatedly survives until one crisis results in death.<sup>81</sup> Because treatments are successful until the one

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72. Freyer, *supra* note 17, at 387.

73. WHEN CHILDREN DIE, *supra* note 8, at 75. The article lists four possible trajectories; however, the *sudden, unexpected death trajectory* (e.g., car crash, SIDS) and the *death from lethal congenital anomaly* (e.g., condition leading to death immediately following birth) are beyond the scope of this Note.

74. *Id.*

75. *Id.*

76. *Id.*

77. *Id.* at 73-74.

78. *Id.* at 73.

79. *Id.* Approximately forty-five percent of the Cystic Fibrosis patient population is age eighteen or older. Cystic Fibrosis Foundation, About Cystic Fibrosis: Statistics, <http://www.cff.org/AboutCF> (last visited Oct. 7, 2010).

80. WHEN CHILDREN DIE, *supra* note 8, at 75.

81. *Id.*

time they are not, this rollercoaster trajectory may cause patients, parents, and even medical professionals to feel unprepared for the final failure of treatment.<sup>82</sup> However, early recognition that the patient has reached the final stage of his or her illness allows the goal of care to shift to maintaining physical and emotional comfort.<sup>83</sup> The turning point is often when life-sustaining medical treatment is more burdensome than beneficial.<sup>84</sup>

Duchenne Muscular Dystrophy (DMD), affecting males only, is one such disease that follows this dying trajectory. It occurs as a result of mutations in the dystrophin gene, and these mutations result in progressive muscle degeneration.<sup>85</sup> DMD, by its very nature, is an insidious disorder because patients with DMD typically do not demonstrate symptoms until ages two or three years old.<sup>86</sup> Most patients are diagnosed at five years old, typically after parents observe delayed developmental milestones or abnormal muscle function in the child.<sup>87</sup> As the young man enters his early teens, the muscles of the respiratory system begin to decline, leading to a need, first for non-invasive ventilation, and then for invasive ventilation via a tracheostomy as DMD progresses.<sup>88</sup> Young adults with DMD often suffer heart failure in their teens, and DMD is typically fatal during their teens or twenties.<sup>89</sup> Nevertheless, the fatal prognosis in no way means the young man should be treated as an invalid. For example:

[The young man] may not need a wheelchair until sometime between the ages of 10 and 12, and even then may not need it full time, but [parents] may want to prepare him for this eventuality ahead of time. If the child senses that a wheelchair is something the parents have long dreaded or that every therapy has been directed at “keeping him out of a wheelchair,” then the event almost has to seem like a defeat.<sup>90</sup>

The finality of this trajectory requires that families respectfully acknowledge that the disease will continue to progress despite the patient’s efforts to “fight.”<sup>91</sup> Because the progression of this disease is unavoidable, it is vital that families

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82. *Id.*

83. *Id.*

84. *Id.* at 76.

85. Katherine Bushby et al., *Diagnosis and Management of Duchenne Muscular Dystrophy, part 1: Diagnosis, and Pharmacological and Psychosocial Management*, 9 LANCET NEUROLOGY 77, 77 (2010).

86. Muscular Dystrophy Association, *Journey of Love: A Parent’s Guide to Duchenne Muscular Dystrophy*, ch. 2, <http://www.mda.org/publications/journey/2-2.html> (last visited Nov. 2, 2010) (noting that the first signs often appear innocuous, such as difficulty transferring from a seated position to a standing position).

87. Bushby, *supra* note 85, at 81.

88. Muscular Dystrophy Association, *supra* note 86, ch. 4, <http://www.mda.org/publications/journey/intro.html> (last visited Nov. 15, 2010).

89. *Id.* ch. 10.

90. *Id.* ch. 4.

91. *See id.*

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understand the ultimate prognosis.<sup>92</sup>

The second trajectory outlines the patient with a potentially curable disease, such as cancer, who initially responds to treatment but eventually dies of the disease or its further treatment.<sup>93</sup> Typically, the patient responds positively to aggressive and possibly life-threatening treatment and may receive a favorable prognosis.<sup>94</sup> However, in the event of a relapse, the patient must then decide if he or she wishes to continue treatment with a curative intent.<sup>95</sup>

Patients receiving stem cell transplantation (SCT) often follow the second dying trajectory.<sup>96</sup> Although the overall cure rate of childhood cancer is 70%, the survival rate for patients needing pediatric SCT is much lower.<sup>97</sup> Patients receiving this treatment modality experience a significant decrease in their quality of life, and families often struggle with the uncertain prognosis.<sup>98</sup> For example, patients with acute myeloid leukemia (AML), have a 40% to 60% five-year survival rate.<sup>99</sup> However, after a relapse, the survival rate is reduced to 25%.<sup>100</sup> As previously noted, patients on the second trajectory often die of the treatment itself.<sup>101</sup>

Morbidity during the immediate transplantation period is significant, with patients experiencing mucositis, pain, veno-occlusive disease, and respiratory complications. These children are also more likely to die of treatment-related complications than are those who die secondary to a malignancy but without transplantation as part of their treatment. Furthermore, patients, family members, and their clinicians experience significant physical, emotional, and spiritual distress.<sup>102</sup>

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92. *Id.* (illustrating that families should avoid imposing expectations on the child that will result in his feeling like a "failure").

93. *WHEN CHILDREN DIE*, *supra* note 8, at 75.

94. *Id.*

95. *See id.*

96. *See* Justin N. Baker et al., *A Process To Facilitate Decision Making in Pediatric Stem Cell Transplantation: The Individualized Care Planning and Coordination Model*, 13 *BIOLOGY BLOOD & MARROW TRANSPLANTATION* 245, 245 (2007) [hereinafter ICPC I]; *see also* *WHEN CHILDREN DIE*, *supra* note 8.

97. *WHEN CHILDREN DIE*, *supra* note 8, at 75; ICPC I, *supra* note 96, at 245.

98. ICPC I, *supra* note 96, at 245-46.

99. *Id.* at 245-46 (describing survival rates for patients receiving allogenic stem cell transplants). This is from a sibling or parent; an unrelated donor may also be used. *See* National Cancer Institute, Bone Marrow Transplantation and Peripheral Blood Stem Cell Transplantation, <http://www.cancer.gov/cancertopics/factsheet/Therapy/bone-marrow-transplant> (last visited Nov. 9, 2009).

100. ICPC I, *supra* note 96, at 246 (illustrating the poor survival rate associated with relapse in patients initially treated with allogenic transplantation).

101. *Id.* (noting that these patients are more likely to die of treatment-related complications than are those who die secondary to a malignancy but without transplant).

102. *Id.*



The above information and clinical examples illustrate the importance of prognostication in medical decision making. Unrealistic prognostic expectations may lead families to ask for medically inappropriate interventions that create “inescapable suffering” and offer no curative benefit.<sup>103</sup> These unrealistic expectations are the primary source of contention between the adolescent patient, the parents, and the care team.<sup>104</sup>

### *A. Impaired Parental Decision-Making Capacity*

Parents are often the most reluctant to accept a child’s fatal prognosis.<sup>105</sup> Despite the fact that earlier parental recognition of this prognosis is associated with a greater treatment emphasis on reducing patient suffering, most families remain hopeful that their child will be the one to “beat the odds.” There is a considerable delay in recognizing that their child has no realistic chance for a cure.<sup>106</sup> The realization that a child will not survive comes to each parent differently, and is referred to as the “parent-defined end-of-life care period.”<sup>107</sup> In the majority of cases, the physician documented that the patient entered the end-of-life care period three months before the parent-defined end-of-life care period.<sup>108</sup> For example, in a recent study surveying the parents of children who died from cancer, the first recognition that the child had no realistic chance for survival occurred, on average, 106 days prior to death.<sup>109</sup> In contrast, the physician first documented that the patient had begun a dying trajectory 206 days prior to death.<sup>110</sup>

The majority of patients in this study had previously undergone the standard treatment for their cancer. At the time of the study, 74% of patients were enrolled in a research protocol.<sup>111</sup> Although most parents remembered the care team discussing the fact that their child had no realistic chance for cure, less than half of these parents reported understanding that their child’s condition was terminal through this discussion.<sup>112</sup> As a result of this research, palliative care teams must now be aware that a formal discussion is not an effective means of communication for more than half of these families.<sup>113</sup>

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103. *Id.*

104. *See id.* at 246-50.

105. Joanne Wolfe et al., *Understanding of Prognosis Among Parents of Children Who Died of Cancer: Impact on Treatment Goals and Integration of Palliative Care*, 284 JAMA 2469, 2469 (2000).

106. *Id.*

107. *Id.* at 2470, 2472.

108. *Id.* at 2473.

109. *Id.* at 2471.

110. *Id.*

111. *Id.*

112. *Id.* at 2472. Ninety percent of parents felt that it was appropriate to discuss this topic, but only sixty-two percent of parents were uncomfortable with the manner in which it was discussed.

113. *Id.* Thirty percent of parents reported that this understanding came from a perceived

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This two-part study first documented the parents' primary goal of treatment during the parent-defined end-of-life period. After the child's death, parents were asked what the goal should have been to ascertain if these preferences had changed. Twenty-eight percent of participating parents reported that their primary goal of pursuing cancer-directed therapy had been to cure cancer. However, after their child's death, only 13% of parents still believed that the primary goal of cancer-directed therapy should be to cure. On the other hand, during the end-of-life period, only 13% of parents chose cancer-directed treatment primarily for the purpose of lessening suffering. Yet after their child's death, 34% of parents stated that this should be the primary reason for choosing to continue care. Finally, 15% of parents said that they based their final treatment decisions on extending the life of their child without hope of a cure. Only 6% felt, after their child's death, that this should be the primary goal.<sup>114</sup>

The study then compared the physician's purpose for treatment decisions during the patient's final month of life with the parent's purpose for treatment decisions. Of the patients who continued to receive cancer-directed therapy during this period, 42% of physicians reported that the purpose of the cancer-directed treatment was to reduce suffering.<sup>115</sup> Yet, only 19% of parents stated that reducing suffering was the primary goal of the treatment.<sup>116</sup> More than half of the parents surveyed reported that the overarching goal of therapy was to extend life during this period, while simultaneously reporting that the purpose of symptom management was to lessen suffering.<sup>117</sup> In contrast, 79% of bereaved parents responded that the primary goal of any treatment during the end-of-life period should be to lessen suffering.<sup>118</sup>

Alternatively, the study demonstrated that when both the physician and the parent can come to a consensus about the prognosis at a minimum of fifty days prior to death, parents are more satisfied with the quality of palliative care.<sup>119</sup> Thirty-seven percent of parents who met this criterion felt very prepared for the symptoms their child experienced during the last month of life.<sup>120</sup> Additionally, 50% of the interviewed physicians described the patient's death as very peaceful.<sup>121</sup> These statistics may not seem persuasive at first glance. However, when the consensus was reached with less than fifty days remaining, only twenty percent of parents felt prepared and only twenty-six percent of physicians stated

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change in their child's appearance or behavior. Nine percent reported that this understanding came from a feeling or dream. *Id.*

114. *Id.*

115. *Id.*

116. *Id.*

117. *Id.*

118. *Id.*

119. *Id.* at 2473.

120. *Id.*

121. *Id.*

the death was peaceful.<sup>122</sup>

Overall, these data suggest that the end-of-life decisions made by parents, although they may assuage parental grief, do not help to ease the child's suffering. These statistics may also provide evidence that parental denial is the root of most end-of-life conflicts.

*B. A Gestalt Entity: Understanding Prognosis Through Intuition and Experience*

Few researchers have formally investigated the end-of-life preferences of terminally ill adolescents.<sup>123</sup> Focusing instead on the preferences of parents and clinicians, the patient's viewpoint went unheard in previous population-centered research. Fortunately, the past five years have produced research employing new methodologies, each carefully designed to elucidate this information scientifically yet sensitively.<sup>124</sup> While the number of studies may be limited, the conclusions provide invaluable insight into the heart of this unique population. In one such study, a seventeen-year-old young man remarked:

We've been through the main steps . . . if it was going to work, probably it already would have worked. Stuff like the radiation, the chemo stuff, and then the experimental chemo, and we have been through several chemos and stuff, so I figured if it was going to slow it down or stop it, you know, it would have done it by now. And, if it hadn't done it by now, it's just going to grow, so I may as well be at home having fun.<sup>125</sup>

In contrast to the delay in recognition by many parents, this comment reflects the realism many terminally ill adolescents have concerning their own prognosis.<sup>126</sup> Perhaps unique to pediatrics, these patients will often accurately describe their prognosis even if their parents attempt to withhold the information.<sup>127</sup> When compared to clinically similar adults, pediatric patients are

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122. *Id.* In a similar study, a physician stated, "She would have an easier death than if we had done a lot of manipulation with machines," when asked what influenced recommendations to parents. Hinds et al., *supra* note 6, at 9152 (showing a general physician preference for less invasive end-of-life care treatments).

123. Hinds et al., *supra* note 6, at 9146.

124. *See, e.g., id.* This study interviewed multiple adolescents, their parents, and their physicians regarding end-of-life care decisions.

125. *Id.* at 9150.

126. Compare Wolfe et al., *supra* note 105, at 2469 (arguing that considerable delay exists in parental recognition that children have no realistic chance for cure), with Hinds et al., *supra* note 6, at 9153 ("Patients [aged 10-20] in this study were able to accurately identify their treatment options and understood that their death would be one of the outcomes of their decision.").

127. *See* Leslie S. Kersun & Eyal Shemesh, *Depression and Anxiety in Children at the End of Life*, 54 PEDIATRIC CLINICS N. AM. 691, 694 (2007) (noting that dying pediatric patients know significantly more about their disease than is expected when one considers the information provided to them).

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more aware of the significance of their illness and are more perceptive to the emotional isolation from their families.<sup>128</sup>

Even when terminally ill pediatric patients are not included in discussions regarding prognosis, they systematically learn about their disease through its predictable stages, resulting in an accurate assessment of their prognosis.<sup>129</sup> The first stage is the recognition that the disease is serious, and is closely followed by the second stage, the realization that medication and treatment are necessary.<sup>130</sup> The patient also learns the taboos of sickness and death, discovering this is not a welcome topic of discussion.<sup>131</sup> The third stage marks an understanding of the purposes and implications of special procedures, such as the possibility of death from chemotherapy.<sup>132</sup> The fourth stage is that of recognition and acceptance, whereby patients recognize that their condition may be permanent, and comprehend that relapses often result in death.<sup>133</sup> The fifth and final stage brings about the realization that there are a finite number of treatments available and that a cure is likely not possible.<sup>134</sup> A child's progression through these stages occurs irrespective of age or intelligence.<sup>135</sup> Rather, the stages are determined and defined by the patient's life experiences.<sup>136</sup> There is substantial evidence suggesting that an adolescent patient will consider these experiences when making a decision regarding LSMT, and that a patient will also evaluate the potential outcomes and the impact of this decision on others, including "loved ones, staff, and future patients unknown to them."<sup>137</sup>

Research demonstrating the value of individual experiences unhinges the strongest arguments against adolescent medical decision making.<sup>138</sup> Critics argue that a minor's medical decisions are based on a limited world view, are not "part of a well-conceived life plan," and do not account for future consequences.<sup>139</sup> As suggested by one psychiatrist, the reason for abridging autonomy is the "recognition that although he may be [competent, the limitations of his experience have] distorted his capacity for sound judgment."<sup>140</sup> Lainie Ross, in her article, *Health Care Decisionmaking by Children: Is It in Their Best*

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128. *Id.*

129. *Id.*

130. WONG, *supra* note 30, at 295.

131. *Id.*

132. *Id.*

133. *See id.*; *see also* Kersun & Shemesh, *supra* note 127, at 694.

134. *See* WONG, *supra* note 30, at 295.

135. Kersun & Shemesh, *supra* note 127, at 694 (noting the surprising fact that a four-year-old child "may understand more about a disease and prognosis" than a much older child).

136. *Id.*

137. Hinds et al., *supra* note 6, at 9152-53.

138. *See id.* (discussing the value of each patient's experiences and preferences).

139. Lainie Friedman Ross, *Health Care Decisionmaking by Children: Is It in Their Best Interest?*, 27 HASTINGS CENTER REP. 41, 42 (1997).

140. *Id.* at 43 (quoting psychiatrist Willard Gaylin).

*Interest?*, furthers this argument by stating that decision-making authority sacrifices long-term autonomy in the name of present-day instant gratification.<sup>141</sup> Her theory asserts that intermediate autonomy must be sacrificed in order for a minor to eventually gain the life and decision-making experience required to develop long-term autonomy.<sup>142</sup> However, these arguments are inappropriate when applied to the adolescent on a dying trajectory. Critics of adolescent autonomy, such as Ross, appear ignorant of the fact that a terminally ill minor does not have the opportunity to consolidate a lifetime of experiential learning with long-term autonomy.<sup>143</sup> A terminally ill teen's decision to forego a second or third round of experimental chemotherapy is very different from that of the teen refusing to seek treatment for anorexia because she cannot conceptualize the harm she is doing to her body.<sup>144</sup> The adolescent patient has the proven ability to understand the prognosis after consolidating his or her experiences and can therefore consider the outcomes of a decision in the short term (e.g., side effects of an experimental drug), the immediate term (e.g., extending the dying trajectory), and the longer term (e.g., dying).<sup>145</sup> The decisions made during the end-of-life stage are the final decisions afforded adolescent patients, and teens will therefore employ "a lifetime's worth of experience" when making their final choices.

### III. THE LEGAL AND MEDICAL FRAMEWORKS FOR ADOLESCENT DECISION MAKING

"[T]he experience, perspective, and power of children' [should] be taken most seriously," wrote Dr. William G. Bartholome in the first publication of the Informed Consent, Parental Permission, and Assent Statement by the American Academy of Pediatrics (AAP) Committee on Bioethics.<sup>146</sup> Yet nearly twenty years later the significance of the experiences and perspectives of many adolescents is still being questioned in the realm of medical decision making.<sup>147</sup> Unfortunately, this has resulted in inconsistent case outcomes and irreparable harm to the vulnerable family unit during a time of medical crises.<sup>148</sup> This Part outlines the current legal rights and medical perceptions of minors. Section A

141. *Id.* at 42-44.

142. *Id.* at 42.

143. Freyer, *supra* note 17, at 383 (criticizing Ross's theory).

144. Ross, *supra* note 139, at 45. Ross's example of "child liberation" run wild is that of a fourteen-year-old diabetic who refuses insulin because her boyfriend's religious beliefs forbid the use of medical care. *Id.* This Note proposes that this is an ineffective example because is not a reflection of a decision by a mature minor.

145. Hinds et al., *supra* note 6, at 9152.

146. Comm. on Bioethics, *Informed Consent, Parental Permission, and Assent in Pediatric Practice*, 95 PEDIATRICS 314, 314 (1995) [hereinafter AAP].

147. Derry Ridgway, *Court-Mediated Disputes Between Physicians and Families Over the Medical Care of Children*, 158 ARCHIVES PEDIATRICS & ADOLESCENT MED. 891, 896 (2004).

148. *Id.*

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discusses the reasonableness of emancipation and the misapplication of *Roper v. Simmons*<sup>149</sup> to adolescent medical decision making. This section also explains the deficiencies of the mature minor doctrine. Section B outlines the American Academy of Pediatrics' recommendations with respect to adolescent assent, dissent, and consent to treatment with a curative intent.

There are ongoing, yet separate, discussions of this issue within the medical and legal communities.<sup>150</sup> The medical community is largely in favor of adolescent medical decision making.<sup>151</sup> For example, a policy statement issued by the American Academy of Pediatrics states that fourteen is the age at which pediatric patients should be permitted to exercise appropriate control over their care.<sup>152</sup> However, the legal community is more conservative, advocating for parental authority in decision making.<sup>153</sup> Few courts are willing to even address this issue, and when they do, the family is scrutinized under the media's microscope.<sup>154</sup>

### A. The Legal Restrictions – From the Impractical to the Unpredictable

#### 1. Status-Based Exceptions

United States federal law has not created a bright-line "age of majority." In its place, each state has created its own laws, often predicated on the political climate, to determine when a teen gains the legal rights of an adult.<sup>155</sup> *Parens patriae*, the proactive philosophy that government ought to protect the welfare of minors,<sup>156</sup> has been invoked by state legislatures to justify governing many rights, such as the legal age for driving, voting, enlisting in the armed services, and the consumption of alcohol.<sup>157</sup> The legislature also sets the age at which parental consent is no longer needed for medical and mental health treatment.<sup>158</sup> In the majority of states, a patient must be eighteen in order to consent to

149. *Roper v. Simmons*, 543 U.S. 551 (2005).

150. See Ridgway, *supra* note 147, at 896 (noting the legal community's focus on case precedent and court assessments); see also AAP, *supra* note 146, at 317 (regarding the adolescent's opinion as the determinative decision-making factor).

151. AAP, *supra* note 146, at 317.

152. See *id.*

153. See Jennifer L. Rosato, *Let's Get Real: Quilting a Principled Approach to Adolescent Empowerment in Health Care Decision-Making*, 51 DEPAUL L. REV. 769, 772 (2002).

154. WHEN CHILDREN DIE, *supra* note 8, at 293.

155. See Norman M. Goldfarb, *Age of Consent for Clinical Research*, 4 J. CLINICAL RES. BEST PRACTICES 1, 1 (2008), [http://www.firstclinical.com/journal/2008/0806\\_Consent\\_Age.pdf](http://www.firstclinical.com/journal/2008/0806_Consent_Age.pdf). *Parens patriae* is a fluid philosophy that can fluctuate with the policy expectations of the day. See Rhonda Gay Hartman, *Coming of Age: Devising Legislation for Adolescent Medical Decision-Making*, 28 AM. J. L. & MED. 409, 411-12 (2002).

156. See Hartman, *supra* note 155, at 411. The degree of this protection varies by political leanings and social demands.

157. See Goldfarb, *supra* note 155, at 2.

158. See Hartman, *supra* note 155, at 419-21.

treatment; however, some states have adopted statutory exceptions based on the adolescent's legal status, including emancipation, personal status, and clinical status.<sup>159</sup>

*(a) Emancipation*

In certain states, a minor may become legally emancipated, or receive the same rights as an adult, before reaching the age of majority.<sup>160</sup> While this may seem to be a possible avenue for securing the right to make medical decisions, a terminally ill minor will almost never qualify for legal emancipation. The typical emancipation process requires that the teen prove that he or she is legally married or living physically apart and financially independent from a parent or guardian.<sup>161</sup> For instance, in Colorado, a minor must prove independence in matters of care, custody, and earnings.<sup>162</sup> In other states, the need for medical care expressly voids emancipation.<sup>163</sup> All told, any showing of financial instability or living dependence on the part of the teen voids the emancipation.<sup>164</sup> This provision is certainly problematic for the critically ill minor because even if it were possible for the teen to be financially independent, emancipation prohibits a parent from being a caretaker for the teen. Appreciably, when a teen is on a dying trajectory, it is not in the best interest of the teen to rely solely on the hospital or private nursing care as his or her end-of-life support system. For these reasons, emancipation is not a realistic avenue for terminally ill minors to achieve autonomy.

*(b) Personal & Clinical Status Exceptions*

Certain states permit a teen to consent to treatment based on his or her

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159. *Id.* at 419-20.

160. The following states do not have an emancipation statute: Arizona, Arkansas, Delaware, Georgia, Idaho, Indiana, Iowa, Kentucky, Minnesota, Mississippi, Missouri, Nebraska, New Jersey, New York, North Dakota, Ohio, South Carolina, Tennessee, Wisconsin. Neither do certain counties in Pennsylvania. Juvenile Law Center, Emancipation in the United States, <http://jlc.org.c25.sitepreviewer.com/index.php/factsheets/emancipationus> (last visited Nov. 10, 2010). While emancipation typically grants the minor the same rights as an adult, a state may still place restrictions on certain freedoms. *See* NEV. REV. STAT. § 129.130 (2009) (prohibiting an emancipated minor from consuming alcohol until age twenty-one).

161. *See, e.g.*, ALA. CODE § 26-13-1 (LexisNexis 2010) (granting relief from disabilities when parents are absent, insane, or dead); ALASKA STAT. § 09.55.590 (2009); ARIZ. REV. STAT. ANN. § 12-2451 (2009); CONN. GEN. STAT. § 46b-150 (2009); FLA. STAT. § 743.015 (2009); HAW. REV. STAT. § 577-25 (2009); 750 ILL. COMP. STAT. 750/30-7 (LexisNexis 2010); KAN. STAT. ANN. § 38-108 (2009); ME. REV. STAT. ANN. tit. 15, § 3506-A (2009); MD. CODE ANN., [Emancipation] § 3-826.1 (LexisNexis 2009); MONT. CODE ANN. § 41-1-501 (2009).

162. COLO. REV. STAT. § 19-1-103 (2005).

163. FLA. STAT. § 743.015 (2009) (stating that emancipation requires an explanation of how the needs of the minor with respect to medical care will be met).

164. *See supra* note 161.

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having special legal status, such as being legally married. Like emancipation, these exceptions also vary by state and generally reflect the political climate. For instance, in Texas, a teen can consent to medical treatment if he or she is in the military or married because this is automatically emancipating.<sup>165</sup> The logic behind both the marriage- and military-status exceptions is similar: both create a responsibility between a minor and a third party, which obviates the parent-child relationship.<sup>166</sup>

Interestingly, some states permit a minor to consent to medical treatment if the minor has become a parent. Depending on the state, a minor-parent's ability to consent to health care is defined in one of three ways: (1) a minor can consent to the care of her child, but cannot consent to her own care unless it is pregnancy related;<sup>167</sup> (2) a minor can consent to the health care of her custodial child and for herself; or (3) a minor can consent to her own health care if she has given birth previously.<sup>168</sup> The third provision is the broadest, as it is not necessary that the minor have custody of the child.

The above pregnancy-related state laws assume that minors who become pregnant are, by default, more mature and capable of making complex decisions than those who choose to avoid teen pregnancy. However, research shows that teen motherhood actually restricts social and personal growth, the two tenets of mature decision making.<sup>169</sup> In contrast, the responsibility and emotional toll of a terminal illness is proven to instill in the adolescent patient the ability to evaluate options, weigh consequences, and then make a complex, multi-variable decision.<sup>170</sup> While it seems incongruous that bright-line provisions exist for teens that give birth, these consent provisions demonstrate the inability of the legislature to consider the intrinsic assets which more accurately signify maturity.

## 2. *The Supreme Court as an Adolescent Psychologist*

The judiciary does not often involve itself in adolescent development and psychology. However, in 2005, the Court directly addressed adolescent maturity and decision-making ability. In *Roper v. Simmons*, the United States Supreme Court invalidated the juvenile death penalty on the grounds that it violated the Eighth Amendment's ban on cruel and unusual punishment.<sup>171</sup> The Court's assessment of juvenile culpability eliminated the "case-by-case," or totality of

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165. TEX. FAM. CODE ANN. §§ 32.003, 101.003 (Vernon 2008).

166. Goldfarb, *supra* note 155, at 1.

167. FLA. STAT. § 743.065 (2009).

168. MINN. STAT. § 144.342 (2009).

169. See KATHLEEN STASSEN BERGER, *THE DEVELOPING PERSON THROUGH CHILDHOOD AND ADOLESCENCE* 447 (2003).

170. *Id.*; see also Hinds et al., *supra* note 6, at 9152-53.

171. 543 U.S. 551 (2005). This reaffirmed its prior holding that "[c]apital punishment must be limited to those offenders . . . whose extreme culpability makes them 'the most deserving of execution.'" *Id.* at 568 (quoting *Atkins v. Virginia*, 536 U.S. 304, 319 (2002)).



circumstances analysis, which had been the cornerstone of previous judicial evaluations of capacity. “In capital cases, the Constitution demands that the punishment be tailored to both the nature of the crime itself and to the defendant’s personal responsibility and moral guilt.”<sup>172</sup> Prior to *Roper*, this required an inquiry into the “degree of harm inflicted on the victim, as well as to the degree of the defendant’s blameworthiness.”<sup>173</sup>

Invalidating the longstanding situational analysis, the *Roper* Court opined that juvenile culpability is automatically mitigated by the three inflexible realities of adolescent maturity: (1) adolescents are impulsive due to an underdeveloped sense of responsibility;<sup>174</sup> (2) adolescents are susceptible to negative influences and peer pressure, in part because of their limited “control . . . over their . . . environment”;<sup>175</sup> and (3) adolescents have incomplete character formation.<sup>176</sup> In essence, the majority held that all teenagers react and respond to situations identically. Although multiple developmentalists have adduced evidence that an adolescent’s experiences weigh more heavily on maturity than age alone, the Court’s majority concocted a bright-line rule that maturity transforms the moment a teen reaches his or her eighteenth birthday.<sup>177</sup> When applied, a seventeen-year-old high school senior, regardless of past criminal behavior, malice, or intent, is legally of diminished mental capacity and lesser culpability; by comparison, his eighteen-year-old codefendant is deemed to be more mature, and therefore more culpable for the crime, despite any mitigating factors, such as coercion by the seventeen-year-old peer to commit the crime.<sup>178</sup> The defendant in *Roper*, for example, stated that he believed he could “get away with it” because he had not yet turned eighteen.<sup>179</sup> This indicates that the defendant did consider the perceived risk of punishment.<sup>180</sup> It is therefore not implausible to

172. *Id.* at 589; see also *Tison v. Arizona*, 481 U.S. 137, 149 (1987); *Eddings v. Oklahoma*, 455 U.S. 104, 111-112, (1982); *Enmund v. Florida*, 458 U.S. 782, 801 (1982).

173. *Roper*, 543 U.S. at 590 (citing *Enmund v. Florida*, 458 U.S. 782, 815 (1982)).

174. *Id.* at 569 (quoting *Johnson v. Texas*, 509 U.S. 350, 367 (1993)).

175. *Id.*

176. *Id.* at 572-73. These characteristics were argued in the amicus brief filed by the American Medical Association, the American Psychiatric Association, the American Society for Adolescent Psychiatry, and others. It is important to note that the argument indicated that the mental capacity is further diminished in juvenile offenders. Brief of the Am. Med. Ass’n et al. as Amici Curiae Supporting Respondent at 10-16, *Roper v. Simmons*, 543 U.S. 551 (2005) (No. 03-633). For a more comprehensive discussion, see Arshagouni, *supra* note 15, at 340-42.

177. *Roper*, 543 U.S. at 598 (O’Connor, J., dissenting) (noting that the Court’s decision is “premised on three perceived differences between ‘adults,’ who have already reached their 18th birthdays, and ‘juveniles,’ who have not”). See Freyer, *supra* note 17, at 382 (advocating that an adolescent’s experiences are a key facet of developmental growth).

178. *Roper*, 543 U.S. at 600-01 (O’Connor, J., dissenting). Justice O’Connor noted that the fact that juveniles are *generally* less culpable for misconduct than adults does not necessarily mean that an especially depraved seventeen year old cannot be *sufficiently* culpable to merit the death penalty. *Id.*

179. *Id.*

180. *Id.* at 601.

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conclude that a manipulative seventeen-year-old could be substantially more culpable than his or her eighteen-year-old codefendant, yet may still receive a lesser sentence on account of his or her age.

Balancing this distinction against the Court's ruling in *Atkins v. Virginia*, which held that the mentally retarded cannot be sentenced to capital punishment, *Roper* indicates that a minor defendant is of comparable capacity.<sup>181</sup> In *Atkins*, the Court opined:

Because of their impairments . . . [such persons] by definition . . . have diminished capacities to understand and process information, to communicate, to abstract from mistakes and learn from experience, to engage in logical reasoning to control impulses, and to understand the reactions of others.<sup>182</sup>

This reasoning is strikingly similar to the three-factor justification in *Roper*. As noted by Justice O'Connor in her dissent, this similar line of logic falsely equates adolescent maturity with the "major lifelong impairments suffered by the mentally retarded."<sup>183</sup> *Roper*'s notation that the adolescent population engages in impulsive, impetuous, and ill-considered behavior is categorically flawed because it negates the adolescent who does demonstrate mature formal operations and social cognition.<sup>184</sup> This possibility alone warrants individualized scrutiny of each teen's development, and not a general assumption that teens have an underdeveloped sense of responsibility, an increased susceptibility to peer pressure, and an incomplete personal character.<sup>185</sup>

For these reasons, the cavil framework of *Roper* is not a persuasive argument against adolescent medical decision making. First, it is well established that terminally ill adolescents do not have an underdeveloped sense of responsibility.<sup>186</sup> On the contrary, one important study showed that terminally ill teens are often more altruistic than their healthy counterparts.<sup>187</sup> This phenomenon, referred to as the *maturational effect of a life-ending illness on an adolescent*, is often manifested through a teen's conscious choice to participate in a Phase I clinical trial because it may benefit others, even if it might cause personal harm.<sup>188</sup> For example, a nineteen-year-old with a solid tumor made the following remarks about experimental chemotherapy:

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181. *Atkins v. Virginia*, 536 U.S. 304 (2002).

182. *Id.* at 318.

183. *Roper*, 543 U.S. at 602 (O'Connor, J., dissenting).

184. *See id.* at 618.

185. *Id.* at 572-73. These characteristics were argued in the amicus brief filed by the American Medical Association, the American Psychiatric Association, the American Society for Adolescent Psychiatry (and others). It is important to note that the argument indicated that the mental capacity is further diminished in juvenile offenders. *See* Brief of the Am. Med. Ass'n et al. as Amici Curiae Supporting Respondent, *supra* note 176, at 10-16.

186. Hinds et al., *supra* note 6, at 9153.

187. *See id.*

188. *See id.*

If I don't take it, my family would support me, but they don't want me to quit. Grandpa said he would worry himself to death if I don't try it. My boyfriend wants me to take it for him. I don't want to do it but for my family.<sup>189</sup>

The Court's second assertion, that the limited control over a teen's environment results in an undue influence of peer pressure, is also inapplicable to terminally ill teens.<sup>190</sup> Although critically ill teens are extensively limited by their condition, the decision to continue or discontinue treatment is the most personal way of exercising control over their intimate, physical environment.<sup>191</sup> When making a decision regarding treatment, the teen is often subjected to intense peer pressure from loved ones to continue fighting.<sup>192</sup> A willingness to openly discuss and advocate for one's personal beliefs exhibits strength, rather than a susceptibility to peer pressure.<sup>193</sup> Finally, the argument that incomplete character formation prevents a terminally ill teen from making a mature medical decision is an insensitive and inapt assertion. Adolescents on a dying trajectory have complete character formation, in the sense that they are who they are right now, and there is no opportunity for future change. This should be respectfully considered by those questioning an adolescent's capacity for end-of-life decisions.

### 3. *The Mature Minor Doctrine*

The mature minor doctrine is currently recognized in a limited number of states.<sup>194</sup> This doctrine permits an adolescent to make a medical decision free from parental consent if the teen can satisfy criteria both specified and evaluated by the judiciary. The widely adopted criteria are set forth as follows:

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189. *Id.* at 9150.

190. *Roper*, 543 U.S. at 569.

191. *Cf.* Maureen Carroll, *Transgender Youth, Adolescent Decisionmaking, and Roper v. Simmons*, 56 UCLA L. REV. 725, 746 (2009) (arguing that denying transgender adolescents' requests for hormones diminishes their control "over the most personal and fundamental component of their physical environment: their own bodies").

192. Hinds et al., *supra* note 6, at 9150 (noting that many patients felt that family members would want them to continue treatment).

193. *Cf.* Carroll, *supra* note 191, at 746 (noting that when transgendered teens who are "routinely misrecognized by others" take steps to "facilitate intra-and inter-subjective recognition of a core (gendered) self," their actions reflect a strong sense of that core self, not a weak response to peer pressure").

194. Certain states have adopted some form of the mature minor doctrine. These include: Arkansas, Idaho, Illinois, Kansas, Mississippi, Nevada, New Mexico, New York, Ohio, Tennessee, and West Virginia. *See* ARK. CODE ANN. § 9-27-362 (2009); IDAHO CODE ANN. § 39-3801 (2009); MISS. CODE ANN. § 41-41-3(3) (2009); NEV. REV. STAT. § 129.030(2) (LexisNexis 2009); N.M. STAT. § 24-7A-6.21 (2009); *In re E.G.*, 549 N.E.2d 322 (Ill. 1989) (holding that a bright-line consent restriction of eighteen is improper if it restricts the constitutional rights of mature minors); *Younts v. St. Francis Hosp. & Sch. of Nursing, Inc.*, 469 P.2d 330 (Kan. 1970); *Lacey v. Laird*, 139 N.E.2d 25 (Ohio 1956); *Cardwell v. Bechtol*, 724 S.W.2d 739 (Tenn. 1987); *Belcher v. Charleston Area Med. Ctr.*, 422 S.E.2d 827 (W. Va. 1992).

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Whether a minor has the capacity to consent to medical treatment depends upon the age, ability, experience, education, training, and degree of maturity or judgment obtained by the minor, as well as upon the conduct and demeanor of the minor at the time of the incident involved. Moreover, the totality of the circumstances, the nature of the treatment and its risks or probable consequences, and the minor's ability to appreciate the risks and consequences are to be considered.<sup>195</sup>

The seminal mature minor case, *Belcher v. Charleston Area Medical Center*, advocated for both the integrity of the decision-making process and the autonomy of the adolescent whose life was at issue.<sup>196</sup> The *Belcher* court held that when a physician is treating a "mature minor," the minor has both the right to consent to a procedure and to elect to withhold a treatment.<sup>197</sup> In *Belcher*, the parents of muscular dystrophy patient Larry Belcher, aged seventeen years and eight months, brought a wrongful death action alleging medical malpractice against the medical center where Larry died.<sup>198</sup> After a common cold exacerbated the effects of his disease, Larry was admitted to the pediatric intensive care unit, where he was intubated for respiratory support.<sup>199</sup> Larry's parents told the physician that they did not want Larry reintubated or resuscitated unless Larry himself requested it, and the physician had his parents sign a progress note indicating that Larry was not to be reintubated in the event of respiratory failure.<sup>200</sup> The physician then formalized the note into a "Do Not Resuscitate" order, and although Larry could communicate and was not cognitively impaired, he did not involve Larry in the decision.<sup>201</sup> Larry went into respiratory arrest the following day, and was neither reintubated nor resuscitated.<sup>202</sup> His parents contended, and the court agreed, that Larry should have been consulted prior to the issuance of the "do not resuscitate" order. Thus, the court's holding recognized the "mature minor" exception.<sup>203</sup>

Although *Belcher* is not the only mature minor case, and this doctrine varies by court, *Belcher* uniquely captured the underlying policy of the doctrine. The court turned a medical assumption into irreducible dicta:

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195. *Cardwell*, 724 S.W.2d at 748. This standard was reaffirmed in the decisive mature minor case of *Belcher*, 422 S.E.2d at 827.

196. *Belcher*, 422 S.E.2d 827 (W. Va. 1992); see also Hartman, *supra* note 157.

197. *Belcher*, 422 S.E.2d at 836-38 (recognizing a mature minor exception to the common law parental consent rule). The court rejected the argument that this applies only to the consent to treatment as opposed to assent, or, affirmatively seeking treatment instead of allowing treatment to be administered or withheld. *Id.*

198. *Id.* at 830.

199. *Id.*

200. *Id.*

201. *Id.*

202. *Id.*

203. *Id.* at 830-31.

It is difficult to imagine that a young person who is under the age of majority, yet, who has undergone medical treatment for a permanent or recurring illness over the course of a longer period of time, may not be capable of taking part in decisions concerning that treatment.<sup>204</sup>

In other words, the weight of this reasoning provides a legal foundation for the argument that experience, rather than age, is a more reliable indicator of an adolescent's ability to make medical decisions. Unfortunately, while the mature minor doctrine is an important policy shift toward adolescent autonomy, there are several flaws that prevent this from being a workable solution for a terminally ill minor.

*(a) The Limitations of the Mature Minor Doctrine*

The mature minor doctrine is an imperfect process for determining whether an adolescent is mature. First, not every state conducts the capacity assessment in the same manner, creating a politicized conflict between state courts.<sup>205</sup> For example, a West Virginia physician can treat a minor free from liability for failure to obtain parental consent if he or she used his or her best medical judgment to assess the minor's maturity.<sup>206</sup> The physician is protected because the *Belcher* court concluded that the decision whether to allow a minor to make medical decisions should be made by the patient's physician.<sup>207</sup> However, if that same patient were to appear before an Illinois state court, the trial judge, and not the physician, would determine whether or not the adolescent is mature enough to make independent medical decisions.<sup>208</sup> Regrettably, neither approach is a best practice for quality patient care. Under a physician-determinative standard, a physician will be placed in the judicial and media spotlight, and he or she will likely be second-guessed during the process.<sup>209</sup> Additionally, because the physician's professional obligation is to the patient and not the parent, the promise of immunity places a significant professional burden on the treating physician.<sup>210</sup> On the other hand, the judicial-determinative standard may produce

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204 *Id.* at 827.

205. Melinda T. Derish & Kathleen Vanden Heuvel, *Mature Minors Should Have the Right To Refuse Life-Sustaining Medical Treatment*, 28 J.L. MED. & ETHICS 109 (2000) (explaining that cases do not systematically resolve this social issue because states come to different conclusions as to who should determine a minor's capacity).

206. *Belcher*, 422 S.E.2d at 837-38.

207. *Id.*

208. *In re E.G.*, 549 N.E.2d 322, 327 (Ill. 1989) (seventeen-year-old leukemia patient refused a blood transfusion based on religious beliefs).

209. Derish & Heuvel, *supra* note 205, at 116 (discussing the weaknesses of the mature minor doctrine).

210. *Id.* See also *WHEN CHILDREN DIE*, *supra* note 8, at 304 (explaining that the physician's primary obligation is to the patient).

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a result biased on the state's adoption of the *parens patriae* philosophy.<sup>211</sup> This is especially problematic for the minor because a minor will not have the right to legal representation during the process unless emancipated, which is highly unlikely, or if a physician suspects abuse.<sup>212</sup> Equally concerning is the fact that judges and juries lack experience in weighing the medical information presented by experts.<sup>213</sup> This may lead to a decision based on a misunderstanding of facts or one unduly influenced by the heartbreak of allowing a child to pass away.

The second problem with the doctrine's capacity assessment is its use of irrelevant factors to measure maturity.<sup>214</sup> Ideally, when applying the doctrine a court should first assess a minor's competence and then determine whether any strong countervailing interests justify circumscribing the minor's autonomy.<sup>215</sup> However, most courts focus on a myriad of external, unrelated factors because they are ill-equipped to properly assess a teen's development.<sup>216</sup> For example, in *Younts v. Saint Francis Hospital & School Of Nursing, Inc.*, the court weighed the semi-conscious state of the mother, the father's unavailability, and the mother's likely consent to the minor's surgery more heavily than the overall maturity of the minor.<sup>217</sup> Even the seemingly well-balanced *Belcher* factors, when scrutinized, favor external milestones. For instance, this analysis requires a court to consider the ability and level of education separately from the minor's degree of maturity. As emphasized previously, judging a terminally ill minor by extrinsic assets penalizes the minor for the physical limitations of his or her illness.<sup>218</sup> Also in error, the court evaluates age rather than maturity, although studies have proven that a terminally ill teen is often more mature than an older, healthy peer.<sup>219</sup>

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211. Cf. Derish & Heuvel, *supra* note 205, at 117.

212. *Id.* at 116 (noting that the present medical-legal system does not afford a terminally ill minor access to an attorney or the court unless she wishes to be emancipated or is abused/neglected).

213. WHEN CHILDREN DIE, *supra* note 8, at 317.

214. Jennifer L. Rosato, *The Ultimate Test of Autonomy: Should Minors Have a Right To Make Decisions Regarding Life-Sustaining Treatment*, 49 RUTGERS L. REV. 1, 22 (1996) (disfavoring the courts' use of a broad-reaching factor analysis).

215. See *id.* (questioning whether courts actually apply a mature minor doctrine when making a decision regarding adolescent autonomy).

216. See *id.*; see also WHEN CHILDREN DIE, *supra* note 8, at 317 (explaining that both judges and juries have difficulty basing decisions on technical, medical information).

217. *Younts v. St. Francis Hosp. & Sch. of Nursing, Inc.*, 469 P.2d 330, 338 (Kan. 1970). The use of factors unrelated to maturity has been in place for as long as the doctrine as existed. The *Belcher* court cites to the *Bakker v. Welsh* decision, where the court considered whether adult relatives accompanied the minor to the physician, that the minor was near the age of majority, and that the minor's father impliedly consented to treatment. *Belcher*, 422 S.E.2d at 836 (citing *Bakker v. Welsh*, 108 N.W. 94 (Mich. 1906)).

218. See generally Part II.

219. *Id.*

*(b) When Parents Oppose the Minor's Right To Refuse Treatment*

Even in states where the mature minor doctrine permits a teen to consent to treatment, courts weigh heavily against the minor's right to refuse treatment if there is any opposition from parents, guardians, adult siblings, and other relatives.<sup>220</sup> While the doctrine may overcome the legal presumption that a minor is incompetent, it fails to prevail over the assumption that parents will act in the best interest of their child.<sup>221</sup> Courts often afford the assumption of "parent knows best" the weight of a legal presumption.<sup>222</sup> However, when parents are faced with the imminent death of a child, their judgment is often clouded by unspeakable grief and loss of control.<sup>223</sup> For example, when asked about end-of-life decisions, the mother of a fourteen-year-old end-stage cancer patient remarked, "I am . . . prolonging the inevitable until a cure comes along . . . . I want her to be healed. I keep telling her to hold on . . . ." <sup>224</sup>

This profound sense of powerlessness is often exacerbated by exhaustion and the atmosphere in the Pediatric Intensive Care Unit.<sup>225</sup> In some instances, other relatives or advisors may pressure parents to continue LSMT, despite the adolescent's wishes.<sup>226</sup> Finally, parents may choose a Phase I clinical trial to prolong their child's life or to make their teen's life seem more meaningful, because the loss feels so senseless otherwise.<sup>227</sup> The following two statements were made by the parents of end-stage cancer patients:

What my daughter goes through would be very important to another child. It's not just to save her but children in the near future that could possibly come down with this particular type of cancer...

*Mother of a 17-year-old girl with a solid tumor*<sup>228</sup>

220. See, e.g., *In re E.G.*, 549 N.E.2d 322, 328 (Ill. S.Ct.1989); *In re Swan*, 569 A.2d 1202 (Me. 1990); *In re Rosebush*, 491 N.W.2d 633 (Mich. App. 1992); *Belcher*, 422 S.E.2d at 827 (W. Va. 1992).

221. See Derish & Heuvel, *supra* note 205, at 117 (noting the almost automatic assumption that, as long as physicians provide adequate information, parents will always make the best decisions about medical care).

222. *Id.*

223. *Id.*

224. Hinds et al., *supra* note 6, at 9151.

225. See Annette R. Pejic, *Verbal Abuse: A Problem for Pediatric Nurses*, 31 PEDIATRIC NURSING 271 (2005) (noting that this type of stress is proven to reduce a parent's ability to control emotional outbursts). These emotions also affect a parent's judgment and self-control. For example, there is a positive correlation between the severity or unpredictability of the child's condition and the parent's likelihood of verbally abusing a nurse or allied health professional. *Id.*

226. Cf. Derish & Heuvel, *supra* note 205, at 117 (describing tensions between adolescents who wish to refuse LSMT and parents who disagree).

227. Hinds et al., *supra* note 6, at 9151 (quoting a parent's reasoning for choosing trial).

228. *Id.*

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Hopefully and in someway, we will be able to get through all this and go on with our life, but if it does not work out, we'll want someone else to benefit.

*Mother of a 17-year-old girl with a brain tumor*<sup>229</sup>

While most parents try to make the best possible decision regarding end-of-life treatment, the reality is that the decision to postpone a patient's imminent and inevitable death can greatly increase suffering. When interviewed, an eighteen-year-old cancer patient described his reasons for discontinuing treatment, even though there was a chance it would prolong his life:

I want to die. I just want to get it over with . . . it feels like I'm being tortured, not tortured, not forced, they are not purposely doing this, but they might as well just chain me up to the wall and put needles in my arms.<sup>230</sup>

Supporting this theory is a 2008 study analyzing the feelings of bereaved parents toward end-of-life treatment options. The children of the participating parents had undergone a median of three different treatment regimens, including chemotherapy, radiation, and stem cell transplantation.<sup>231</sup> The study first interviewed parents during the tenure of their child's illness. Researchers asked the parents to report their goals of cancer-directed therapy, first upon diagnosis and then upon realizing that their child's cancer was terminal.<sup>232</sup> The participants were then contacted one year or more after their child's death and asked to respond to a clinical vignette. The vignette assessed parents' willingness to recommend chemotherapy to another family whose child had no realistic chance for cure.<sup>233</sup> The study concluded that, even if they had chosen experimental treatment for their own child, the majority of bereaved parents would not recommend experimental treatment for incurable cancer to other similarly situated families.<sup>234</sup> Although most parents chose additional treatment with the goal of curing their child's cancer, the extent of patient suffering was higher than both parents and researchers anticipated.<sup>235</sup> The parents who felt their child had

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229. *Id.*

230. *Id.* at 9150.

231. Jennifer W. Mack et al., *Parents' Views of Cancer-Directed Therapy for Children With No Realistic Chance for Cure*, 26 J. CLINICAL ONCOLOGY 4759, 4760 (2008). The patients in this study "died with progressive cancer, not as a result of treatment complications." *Id.* at 4761. Patients who received treatment for incurable cancer were comparable to those who did *not* receive such therapy with respect to parent race, site of care, duration of disease, and duration of the end-of-life period. *Id.* Interestingly, parents whose children received treatment for incurable cancer in the end-of-life "period tended to have higher educational attainment and income" than the parents whose children did not receive such therapy. *Id.* They also "used . . . a greater number of different cancer regimens" and they chose "to discontinue therapy [significantly] closer to the time of death." *Id.*

232. *Id.*

233. *Id.*

234. *Id.*

235. *Id.* at 4762-63.



suffered without benefit reported they would not recommend this course of treatment to the hypothetical family presented in the vignette.<sup>236</sup>

Although inconsistent with the current legal framework, pediatric and adolescent psychologists also recommend that the competency and motivations of the parents be assessed if they object to a minor's refusal of LSMT.<sup>237</sup> If the patient expresses a difference of opinion, a parent or guardian's grief should not overly influence the final medical judgment.<sup>238</sup> The mature minor doctrine will not truly be effective until minors are afforded an adult's right to consider another person's preference for continuing LSMT—*without* being bound by that preference.<sup>239</sup>

*(c) An Ill-Equipped Judiciary*

Another significant problem with the mature minor provision is the costly, disruptive, and unpredictable litigation process that it engenders.<sup>240</sup> The side effects of litigation can be very emotionally injurious.<sup>241</sup> The judicial process subjects the patient to the global media and frequently creates hostility within the family and care team.<sup>242</sup> In several reported legal disputes, a change in the patient's medical status renders the court-authorized interventions inappropriate; nevertheless, the family's integrity has already been compromised by the relentless media attention paid to court-mediated pediatric disputes.<sup>243</sup> In the rare case that the judicial intervention does reach a resolution, the historical record suggests that judges are more than willing to override a mature minor patient's preferences.<sup>244</sup> In a survey of fifty judicial interventions, courts acknowledged the pediatric patients' preferences in only ten of the disputes.<sup>245</sup> The survey also showed a judicial disregard for the physicians' recommendations when the disputes concerned life-threatening or disabling conditions.<sup>246</sup> Although many of the courts purported to apply the mature minor doctrine, the most frequently cited reason for the decision to override the patient's choice was an interest in

236. *Id.* at 4761-63.

237. Telephone Interview with Donna J. Follansbee, Ph.D., Research Consultant at The Barbara Davis Center for Childhood Diabetes (Nov. 10, 2009) [hereinafter Follansbee Interview].

238. *Id.* (adding that the motives of a parent's refusal of LSMT must also be reviewed, as this can occur out of exhaustion or depression).

239. See Derish & Heuvel, *supra* note 205, at 117.

240. WHEN CHILDREN DIE, *supra* note 8, at 318.

241. See Ridgway, *supra* note 147, at 896.

242. *Id.*

243. *Id.* at 896.

244. *Id.* at 896.

245. *Id.* at 891. "Courts acknowledged the pediatric patients' views in only 10 of the disputes (9 of the 19 cases involving adolescents and 1 of the 31 cases involving children younger than 12 years)." *Id.*

246. *Id.* at 891.

protecting children's health.<sup>247</sup> One can fairly question whether this justification is a reasonable interest or a mere political cloak, because preserving health is not an issue if the patient is on a dying trajectory.

Further complicating the issue is the lack of reliable case precedent.<sup>248</sup> Most rulings made in response to physicians seeking judicial intervention to enforce treatment for minors against the wishes of the parents do not result in court-published opinions.<sup>249</sup> The limited number of published opinions that address physician-parent disputes do not adequately address the ethical, legal, and medical issues of the case.<sup>250</sup> Nevertheless, because so few cases exist, these cases establish the legal precedent that shapes subsequent rulings across the United States. When faced with a dispute, state courts often cite other state courts, thereby creating a de facto national jurisdiction for court-mediated pediatric disputes.<sup>251</sup>

Litigation proceedings also place the patient's care team under the professional microscope.<sup>252</sup> Often the result of zealous reporting, this professional scrutiny affects the physician's relationships with both colleagues and other patients. Unlike other technical cases, where outside expert testimony is heard during proceedings, the medical testimony in mature minor cases is usually limited to that of the treating physician's.<sup>253</sup> Because a trial judge and jury lack medical proficiency, the majority of mature minor case summaries are scientifically incomplete when published.<sup>254</sup> Unfortunately, the resultant public record includes inaccuracies, which are often falsely attributed to the treating physician.<sup>255</sup> This inevitable problem places a tremendous professional burden on those physicians forced to seek a judicial intervention in order to fulfill their ethical obligation to their patients.

#### *B. What the Pediatric Team Knows: The Medical Community's Recommendation*

The medical community has recently placed an enhanced focus on patient and family-centered care. Unlike the legalistic approach to medical decision making, the pediatric guidelines mandate the adolescent's involvement, as well as an effort by clinicians to see care through the adolescent's eyes.<sup>256</sup> Although parents may have the legal right to make decisions, pediatric clinicians have an ethical obligation to afford the adolescent an opportunity to discuss his or her

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247. See *id.*; see also Derish & Heuvel, *supra* note 205, at 117.

248. See Ridgway, *supra* note 147.

249. *Id.* at 891.

250. *Id.* at 895-96.

251. *Id.* at 896.

252. *Id.* at 896.

253. *Id.* at 895.

254. *Id.*

255. *Id.* at 895-96.

256. *Id.*

preferences and concerns regarding care.<sup>257</sup> This model imparts upon medical professionals the ethical duties of fidelity and professional integrity.<sup>258</sup> Fidelity, the responsibility of health care professionals to place the interests of their patients first, is at the heart of the patient-centered care model.

The American Academy of Pediatrics (AAP) has adopted a bright-line approach to pediatric patient-centered care.<sup>259</sup> The AAP policy states that pediatric patients should always be included in the decision-making process, and remarks that “indeed, some patients have specific legal entitlements to either consent or to refuse medical intervention.”<sup>260</sup> The AAP further states that physicians should obtain the informed consent of an adolescent patient in the majority of circumstances.<sup>261</sup> However, under the current legal framework, pediatric patients have very little opportunity to provide informed consent to medical treatment.<sup>262</sup> In light of these limitations, the AAP has outlined specific guidelines for obtaining the *assent* of a pediatric patient.<sup>263</sup> These guidelines are directed at pediatric patients of all ages, and are to be modified according to age and development:

1. Helping the patient achieve a developmentally appropriate awareness of the nature of his or her condition.
2. Telling the patient what he or she can expect with tests and treatments.
3. Making a clinical assessment of the patient’s understanding of the situation and the factors influencing how he or she is responding (including whether

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257. *Id.* at 896.

258. WHEN CHILDREN DIE, *supra* note 8, at 303-04. Professional integrity refers to the requirement that physicians act for the benefit of all patients. *Id.* The obligation is typically discussed in reference to the allocation of medical resources. *Id.* at 305. Although relevant, it is beyond the narrow scope of this Note.

259. AAP, *supra* note 146, at 314.

260. *Id.* The AAP states that there must be “persuasive reasons” to do otherwise. *Id.*

261. *Id.* at 314-15. The AAP lists the following components as necessary in order to obtain informed consent:

1. Provision of information: Patients should have explanations, in understandable language, of the nature of the ailment or condition; the nature of proposed diagnostic steps and/or treatment(s) and the probability of their success; the existence and nature of the risks involved; and the existence, potential benefits, and risks of recommended alternative treatments (including the choice of no treatment).
2. Assessment of the patient’s understanding of the above information.
3. Assessment, if only tacit, of the capacity of the patient or surrogate to make the necessary decision(s).
4. Assurance, insofar as is possible, that the patient has the freedom to choose among the medical alternatives without coercion or manipulation.

*Id.* at 315.

262. *Id.* at 315-16.

263. *Id.*

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there is inappropriate pressure to accept testing or therapy).

4. Soliciting an expression of the patient's willingness to accept the proposed care. *Regarding this final point, we note that no one should solicit a patient's views without intending to weigh them seriously. In situations in which the patient will have to receive medical care despite his or her objection, the patient should be told that fact and should not be deceived.*<sup>264</sup>

The AAP has also vehemently argued that a pediatric patient, especially an adolescent, has the full authority to refuse assent.<sup>265</sup> The refusal of assent, also referred to as dissent, should carry considerable weight in the context of participation in clinical research, and clinicians should avoid coercion in treatment whenever possible.<sup>266</sup> According to the AAP, an adolescent's dissent is ethically, if not legally, binding.<sup>267</sup>

In order to successfully integrate the AAP's recommendations, the patient/care team relationship must be based on trust.<sup>268</sup> When the patient is critically ill, maintaining this balance is considerably more difficult because physicians must address palliative care without eroding hope.<sup>269</sup> The patient and family will benefit most from end-of-life care discussions if the physician is skilled in facilitating this conversation.<sup>270</sup> However, most physicians feel unprepared and uncomfortable having any type of end-of-life discussion. According to one survey, only two percent of pediatric oncologists report a rotation on a palliative care service, and thus the most common palliative experiences are of a "trial and error" nature.<sup>271</sup> One survey suggested that some fourth-year medical students are asked by their attending or resident physician to "handle" dying patients because their attending or resident physician is uncomfortable working with these patients, and is seizing the opportunity to displace the responsibility.<sup>272</sup> One such "student reported that he felt that his inept and unguided effort to discuss a patient's preferences for resuscitation 'doomed' the patient to terrible, prolonged death."<sup>273</sup> However, as this behavior is cyclical, the student will likely pass on these cases to other unprepared students when he is finally a resident. This unstructured and unguided approach to palliative care education places patients, families, and care teams at risk for conflicts that are otherwise preventable.<sup>274</sup>

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264. *Id.* (emphasis added).

265. *Id.* at 316.

266. *Id.*

267. *Id.* at 317.

268. Kane & Hilden, *supra* note 12, at 188-89.

269. See Wolfe et al., *supra* note 105, at 2474.

270. Cf. Kane & Hilden, *supra* note 12, at 189.

271. WHEN CHILDREN DIE, *supra* note 8, at 329.

272. Cf. *id.* at 334.

273. Cf. *id.*

274. See *id.* at 329.

The broader legal and medical communities need to recognize what pediatric palliative care specialists already know: the integration of palliative care into the pediatric medicine curriculum will reduce suffering in children who pass away, improve the quality of life for children who survive, and reduce the number of conflicts that end in a courtroom.<sup>275</sup> The Committee on Palliative and End-of-Life Care for Children and Their Families advocates that pediatric residency programs require more extensive preparation in palliative care for those pediatric specialists who care for children with life-threatening medical conditions.<sup>276</sup> The number of pediatric palliative care fellowships should also increase, as this would bring palliative care into the mainstream, removing the discomfort and fear from the field.<sup>277</sup> Moreover, continuing education programs focused on palliative care are a simple way to provide both introductory and advanced education for all pediatric professionals, including nurses and allied health professionals.<sup>278</sup> These strategies will permit a smoother incorporation of palliative care into the patient's care plan, thereby reducing preventable conflicts and the need for judicial intervention.

#### IV. IN THE TRENCHES: THE ICPC/STATUTORY COMBINATION MODEL AT WORK

The subsequent sections outline an individualized, proactive approach to improve the adolescent medical decision-making process. Because a custom-tailored care plan defines true patient-centered care, this Note recommends a two-part solution incorporating the goals of the patient, their family, and their care team.<sup>279</sup> First, pediatric treatment centers should adopt the Individualized Care Planning and Coordination model, and implement this protocol upon diagnosis of a serious illness. Second, this Note advocates for legislative involvement, encouraging state legislatures to enact a fallback statutory provision modeled after Section 24-7A-6.1 of the New Mexico Uniform Health-Care Decisions Act.

##### *A. The Individualized Care Planning & Coordination Model*

The primary purpose of the Individualized Care Planning and Coordination (ICPC) model is to establish a coordinated multi-disciplinary decision-making process.<sup>280</sup> This ICPC model is a three-step progression during which the care team first assesses the patient's understanding of the prognosis, as well as the

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275. *Id.* at 349.

276. *Id.*

277. *Id.*

278. *Id.*

279. See ICPC I, *supra* note 96, at 247 (noting that quality treatment requires a full spectrum of care, including an understanding of the child's personal illness experience and the family's perceptions).

280. *Id.*

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family's comprehension of the illness trajectory.<sup>281</sup> During Phase I, the Relationship phase, the team elucidates the patient's personal treatment goals, as well as their family's treatment goals.<sup>282</sup> This comprehensive needs assessment is then used during the second phase, which consists of a multi-disciplinary negotiation of the best possible treatment plan.<sup>283</sup> The individualized care plan is designed to balance medical and personal goals, maintain family integrity, and foster a trusting relationship among family and care team.<sup>284</sup> The coordinated care plan is implemented in the third and final phase. This includes an immediate action plan and crucial follow-up assessments to ensure that the plan is meeting the patient's needs.<sup>285</sup>

The ICPC model functions best when implemented at diagnosis, as it creates a strong, trust-based foundation of care.<sup>286</sup> The model is then reinitiated if the patient's clinical status worsens, warranting a different course of treatment. For example, the care team reinitiates the first step if the patient's cancer relapses or the muscular dystrophy patient becomes wheelchair or ventilator dependent.<sup>287</sup> This fluidity is one of the many advantages of this model. It enables the care team to prepare the family for loss, thereby lowering the risk of psychological disturbance during the end-of-life and bereavement periods.<sup>288</sup> In other words, the patient and family may hope for the best, while preparing for the worst.<sup>289</sup> The following sections detail the progression of one ICPC cycle.

### 1. Phase I: Relationship

During the first phase, the goal is to facilitate an open dialogue between the care team and the patient/family.<sup>290</sup> This is a three-way conversation, as the care team must understand the personal realities of both the patient and the family and share the necessary information for decision making.<sup>291</sup> The team then prepares a comprehensive needs assessment based on the acquired information for use in the second phase.<sup>292</sup>

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281. *Id.* at 246-47.

282. *Id.* at 248.

283. *Id.* at 249-50.

284. *Id.* at 252.

285. *Id.* at 251.

286. *Id.* at 248-49.

287. *Id.*

288. Justin N. Baker et al., *Integration of Palliative Care Practices into the Ongoing Care of Children with Cancer: Individualized Care Planning and Coordination*, 55 PEDIATRIC CLINICS N. AM. 223, 240 (2008) [hereinafter ICPC II].

289. *Id.*

290. ICPC I, *supra* note 96, at 248.

291. *Id.*

292. *Id.* at 249.

*(a) Empathy for the Illness Experience*

St. Jude Children's Research Hospital physicians recently commented that the ability to listen with an empathetic presence is the most powerful tool in the clinician's arsenal.<sup>293</sup> Because this directly affects patient and parent outcomes, this is arguably the most important practice for mitigating avoidable conflicts. In order to engage in effective communication and subsequently generate the needs assessment, the clinician must appreciate the illness experience from both the patient's perspective and from the perspective of the family.<sup>294</sup> When talking with the patient or family, experts recommend that the clinician be comfortable with silence and create a safe, nonjudgmental atmosphere.<sup>295</sup> Because the adolescent has distinct experiences from those of the parents, this process opens an independent discussion about each party's fears, perceptions, beliefs, preferences, and values.<sup>296</sup> From this, the team can anticipate and understand the patient's and the family's coping strategies, and in so doing, prevent a crisis from becoming a conflict.<sup>297</sup>

*(b) Candid Conversations*

In order to generate a needs assessment, the clinician has the responsibility of sharing relevant information with the patient and the family.<sup>298</sup> As discussed above, the sharing of negative or disappointing news can reduce the quality of the doctor/patient relationship if handled improperly.<sup>299</sup> The ICPC model alleviates this problem by taking an individualized, yet structured approach. In line with the International Pediatric Oncology Society, the model incorporates a protocol for physicians to facilitate this discussion by including the use of exploratory questions, empathetic statements, and validating responses.<sup>300</sup>

During this process, it is critical that the physician identify the main decision-maker within the family unit.<sup>301</sup> This step will help avoid a judicial intervention for two reasons. First, unlike the judge, the clinician is in the best position to evaluate whether the primary decision maker has the capacity to make

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293. *Id.* at 248.

294. *Id.* at 248.

295. *Id.*

296. *Id.*

297. *See id.* at 252.

298. *Id.* at 248.

299. *Id.*

300. *Id.* at 248-49. The following lists different responses recommended by clinicians to facilitate open conversation:

"I want to listen to you tell me more about that."

"What are you hoping for now?"

"We were all hoping for a better result."

301. *Id.* at 252.

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medical decisions.<sup>302</sup> While courts rely on the general legal definition of competent when assessing a parent's decision-making capacity, the clinician has the opportunity to assess the parent's ability to put aside grief in order to make a decision that is in the best interest of the patient.<sup>303</sup> For example, legally competent, educated, and medically savvy parents may still lack the emotional capacity or clear judgment needed during their child's end-of-life period.<sup>304</sup> Other factors, including language barriers, place of residence (i.e., whether hometown is in a rural area with difficult hospital accessibility), or religion may influence the way in which a family makes decisions.<sup>305</sup> In many families, demographic factors influence (1) which family member is the decision-maker and (2) how that person makes medical choices.<sup>306</sup> Once the clinician has identified a particular family's decisive issues, a compromise is more likely to be obtained during conflict resolution.

Second, the clinician must determine what the patient's rights are relative to the rights of the family.<sup>307</sup> If the patient is at all capable of participating in decision making, the physician should elucidate his/her preferences for treatment and quality of life.<sup>308</sup> Even if the parent states that the teen is the primary decision-maker, the clinician must be aware of any undue family pressure placed on the teen to make a specific decision, as this indicates the parent remains the true decision-making force in the family.<sup>309</sup> An understanding of family dynamics ensures that the patient's rights and preferences are being respected to the greatest extent possible in both ethics and the law.<sup>310</sup>

*(c) The Needs Assessment Formula*

The ICPC needs assessment is the most accurate way to assess a minor's decision-making capacity. Unlike other methods, such as the mature minor doctrine, this assessment details a patient's needs according to the domains of his or her personal illness experience.<sup>311</sup> The needs assessment incorporates the relational aspects of care with the patient's physical, social, psychological,

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302. ICPC II, *supra* note 288, at 232.

303. See Follansbee Interview, *supra* note 237.

304. Derish & Heuvel, *supra* note 205, at 117. As evidenced in the previous section, parents often select a treatment plan for their child in order to prolong the inevitable; however, when interviewed after their child's death, they would not recommend the same decision to another family. See Mack, *supra* note 231, at 4761 (stating that parents frequently stated in retrospect that the goal of cancer treatment should be to lessen suffering).

305. ICPC II, *supra* note 302, at 232.

306. *Id.*

307. *Id.*

308. *Id.*

309. See ICPC I, *supra* note 96, at 249 (discussing an adolescent's concern for family when making decisions).

310. *Id.*

311. *Id.* at 248.



cultural, and educational needs. While this may seem like an overwhelming task, the method is successful because the comprehensive needs assessment incorporates feedback from an interdisciplinary team of specialists, including, but not limited to, the medical, psychological, and social services.

The use of a comprehensive assessment negates the fear that the emotional volatility of adolescence might lead a teen to want to discontinue LSMT, equating this withdrawal with adolescent suicide.<sup>312</sup> One of the more potent arguments against adolescent medical decision-making stems from the stereotypical adolescent tendency to have mood swings, feed off the dramatic, and experience exaggerated emotions.<sup>313</sup> However, as the needs assessment incorporates a multidisciplinary approach, every treating service, including psychology/psychiatry, coordinates efforts via shared documentation and frequent meetings.<sup>314</sup> Under the ICPC protocol, the interdisciplinary team members include, but are not limited to, the primary physician (oncologist, orthopedist, etc.) and the psychology, child life service, and the palliative care services.<sup>315</sup>

The ICPC approach differs from the typical system. In a non-ICPC setting, services meet independently to discuss the patient's needs in relation to their specific service. For example, a tumor board will only examine the patient's cancerous tumors, but will not address the side effects or symptoms the patient may be experiencing. The problem with this method is the resultant lack of communication between the services.<sup>316</sup> For example, a recent study found that pediatric oncology care team members often underestimate adolescent psychosocial symptoms, and as a result, the appropriate psychology consultation is not sought.<sup>317</sup>

By contrast, the ICPC model mandates coordination between services. During the interdisciplinary team meetings, the team reassesses the patient's clinical condition, relational care needs, and changes in treatment goals, always

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312. See Kersun & Shemesh, *supra* note 127, at 700 (addressing concerns that the withdrawal of LSMT is type of teen suicide or pediatric physician assisted suicide); see also Jennifer L. Rosato, *The Ultimate Test of Autonomy: Should Minors Have a Right To Make Decisions Regarding Life-Sustaining Treatment*, 49 RUTGERS L. REV. 1, 72 (1996) (differentiating and assuaging the fear that this is the equivalent of teen suicide).

313. Allyn R. Hines & Sharon E. Paulson, *Parents' and Teachers' Perceptions of Adolescent Storm and Stress*, 41 ADOLESCENCE 597, 597-98 (2006) (discussing the public perception that adolescents are emotionally unstable, moody, and troubled). The authors reference G. Stanley Hall's 1904 characterization of the adolescent period as one of "sturm und drang" or "storm and stress." *Id.* at 597-98. One may wonder whether J.K. Rowling had this in mind when she depicted the Durmstrang Quidditch star, Victor Krum, as moody and surly. See J.K. ROWLING, *HARRY POTTER AND THE GOBLET OF FIRE* (2000).

314. ICPC II, *supra* note 288, at 232.

315. *Id.* at 239.

316. *Id.*

317. Kersun & Shemesh, *supra* note 127, at 695.

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modifying the needs assessment when necessary.<sup>318</sup> It makes possible the immediate identification of a depressive disorder or generalized anxiety disorder, and ensures that a true disorder will be distinguished from the expected level of anxiety and sadness resulting from illness.<sup>319</sup> For example, unlike the symptoms of depression in a medically healthy person, "symptoms of anhedonia (lack of interest in pleasurable activities) are considered to be more specific to the diagnosis of depression in the medically ill patients and are less influenced by medical status."<sup>320</sup> Likewise, suicidal ideation in adolescent patients may indicate inadequate pain management, not a genuine desire to end one's life.<sup>321</sup> Therefore, the care team must have an understanding of the course of the patient's illness and his or her normal coping mechanisms, in addition to knowledge of the unique symptoms of a depressive disorder in medically ill patients.<sup>322</sup> Because specialists on the ICPC interdisciplinary team share this information on a regular basis, the care team can immediately respond if the patient shows signs of an impending crisis. While critics of adolescent end-of-life decision making show concern that autonomy will result in suicide, the ICPC process ensures that suicidal ideation will not mask itself as an emotionally healthy request to discontinue care.<sup>323</sup> Treatment decisions are always made after addressing the psychosocial needs of the patient and their family.<sup>324</sup>

## 2. Phase 2: Negotiation

The negotiation phase can begin once the team has created the needs assessment. This next step combines prognosticating and discussing goals of care and specific treatment options" available for the patient.<sup>325</sup> This phase includes a mutual discussion between the patient, family, and care team about the patient's trajectory, medical goals, and life goals.<sup>326</sup> The overriding objective is to reach a

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318. ICPC II, *supra* note 288, at 234.

319. See Kersun & Shemesh, *supra* note 127, at 691-92 (explaining the importance of communication and specialized training in distinguishing the two constructs of symptomatic depression and anxiety versus a disorder).

320. *Id.* at 695.

321. *Id.* at 700. See generally NELSON TEXTBOOK OF PEDIATRICS ch. 40 (18th ed. 2007).

322. See Kersun & Shemesh, *supra* note 127, at 691-92. Comparable to the mainstream external factors for maturity, standardized symptoms of anxiety and depression do not provide an accurate indication in a terminally ill pediatric patient. *Id.*

323. *Id.* at 700 (noting that requests for euthanasia are short-lived if handled in an empathetic manner and the team addresses the following: depression, loneliness, and physical symptoms). After addressing these concerns allows the care team to distinguish between a request for suicide or a request to discontinue LSMT.

324. See ICPC II, *supra* note 288, at 238-39 (stating that psychosocial and spiritual needs are consistently identified as very important to patients and their families, and psychological concerns are frequently under addressed but should be managed as aggressively as physical symptoms).

325. ICPC I, *supra* note 96, at 249.

326. *Id.* at 250-51.

consensus regarding care that matches the patient's medical reality and personal values system.<sup>327</sup> The ICPC model is unique in its incorporation of case scenarios as a demonstrative tool.<sup>328</sup> Contrasting potential clinical care scenarios aids the patient and family in assessing the possible treatment options and potential outcomes.<sup>329</sup> The ICPC model lessens the potential for conflict because supportive care alternatives are always presented alongside the scenario in which treatment with a curative intent is withdrawn.<sup>330</sup> Research has shown that families are more receptive to a discussion of end-of-life care when there is a clear understanding that the goal is to lessen suffering.<sup>331</sup> Parents are less likely to fear discontinuation of LSMT if they are confident that supportive care is immediately available to help their teen reach any remaining personal goals.<sup>332</sup>

Because the negotiation phase necessitates difficult conversations about a patient's possible relapse or death, it is during this phase that the team will likely encounter any discordant steps in the process.<sup>333</sup> "Conflicts may even be productive or beneficial in some situations, for example, when parents may pursue an issue in disagreement rather than capitulating to a course of action and later regretting their silence."<sup>334</sup> Conflict can also benefit the patient's care team, as "overly confident or assertive clinicians may become more sensitive to parental concerns and values."<sup>335</sup> However, the most severe conflicts are destructive rather than productive, and almost always center on treatment decisions.<sup>336</sup> These situations commonly begin with a parent's unrealistic expectations regarding prognosis or a patient's wish to move toward comfort care before the parents are ready to discontinue treatment with curative intent.<sup>337</sup>

When the needs assessment indicates that the discordance is likely to become an insoluble conflict, the ethics committee should be consulted in an effort to reach a resolution.<sup>338</sup> The ethics committee's role within the ICPC is that of moderator.<sup>339</sup> An effective committee is comparable to a confidential forum used to facilitate communication, conflict resolution, and support of

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327. *Id.* at 253.

328. *See id.*

329. *Id.* at 250-51.

330. *Id.* at 251.

331. *Id.*

332. *Id.*

333. *Id.* at 249.

334. WHEN CHILDREN DIE, *supra* note 8, at 308.

335. *Id.* at 308.

336. *Id.* at 308.

337. *Cf.* ICPC I, *supra* note 96, at 249-51 (discussing the challenges of moving from curative treatment to comfort care). The shift for patients and families is gradual and uneven. Parents may need reassurance that they have an appropriate grasp of their child's condition. *Id.* at 251.

338. *Id.* at 249; *see also* ICPC II, *supra* note 302, at 231.

339. *Id.*

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relationships.<sup>340</sup> Its purpose is not to make treatment recommendations, and the family should be reassured of this fact.<sup>341</sup> When the ethics committee is “sprung” on a family, parents quickly become skeptical and hostile toward the hospital as an institution.<sup>342</sup> For instance, one parent remarked,

I think in particular of two times when we made a particular request and were told that the ethics committee would be called. I’m now on the ethics committee at Children’s Hospital here and . . . [I advocate there] that ethics committees not be viewed like the legal system. That’s not helpful or open to families but one other thing to be really frightened about.<sup>343</sup>

Instead, the committee should be presented as a constructive and compassionate resource for families and the medical team.<sup>344</sup> As part of the ICPC care coordination, families should be told of the ethics committee’s existence when they initially learn about the amenities of the treating pediatric care center.<sup>345</sup> Introducing the committee during the negotiation phase mitigates the fear-based reaction that occurs when the committee is called to review a patient’s case without warning. The committee should be considered part of the care team, as a consultation may alter the care plan during the final phase of the ICPC model.

### *3. Phase 3: The Individualized Care Coordination Plan Process*

After arriving at a consensus approach to care through negotiation, the care team, patient, and family can generate a comprehensive care plan.<sup>346</sup> “The ICPC process guides the development of a care plan that takes into account their needs, values, and perceptions, as well as the medical care” appropriate for the patient’s illness.<sup>347</sup> The following is an outline of the domains and the detail required to document the plan for compliance with the model.

- **Disease Management:** This domain must be carefully documented, as it includes the care plan for disease directed medical treatment, including further use of chemotherapy, radiotherapy, and surgery.<sup>348</sup> This domain also directly addresses end-of-life disease management. For example, the patient may document whether they want to continue invasive diagnostic procedures, even including something as basic as a blood draw for

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<sup>340</sup>. *Id.*

<sup>341</sup>. *Id.*

<sup>342</sup>. WHEN CHILDREN DIE, *supra* note 8, at 293.

<sup>343</sup>. *Id.*

<sup>344</sup>. *Id.*

<sup>345</sup>. See ICPC II, *supra* note 288, at 231 (explaining that the ethics committee promotes care coordination and is an integral partner with the palliative care service).

<sup>346</sup>. See ICPC I, *supra* note 96, at 251.

<sup>347</sup>. *Id.*

<sup>348</sup>. *Id.* at 253.

analysis.<sup>349</sup> The care team will also document the patient's specific preferences for LSMT, including ventilator support, antibiotics, kidney dialysis, transfusions, and artificial hydration and nutrition.<sup>350</sup> The ICPC documentation is a proactive strategy to mitigate the atmosphere of crisis and panic that drives many decisions about life-sustaining interventions.<sup>351</sup>

- **Physical Aspects of Care:** The domain involves non-diseased-directed physical treatment. The focus is on symptom management and rehabilitation.<sup>352</sup> The interdisciplinary team members include pain management specialists and physical and occupational therapists. This Note advocates that the team should also include a reproductive endocrinologist because future fertility is a significant concern for newly diagnosed cancer patients.<sup>353</sup> Clinicians used to overlook the fertility implications in pediatric cancer patients.<sup>354</sup> Fortunately, as pediatric cancer survivor rates increase, fertility preservation is becoming an integral part of adolescent cancer treatment.<sup>355</sup> Accordingly, the ICPC

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349. *Id.* at 251.

350. *Id.*; see also WHEN CHILDREN DIE, *supra* note 8, at 298-99 (describing the most common forms of LSMT).

351. See WHEN CHILDREN DIE, *supra* note 8, at 298-99 (noting that LSMT decisions are often made in haste and panic, and this type of decision making leaves all those involved deeply distressed).

352. See ICPC I, *supra* note 96, at 253.

353. See Matthew J. Loscalzo & Karen L. Clark, *The Psychosocial Context of Cancer-Related Infertility*, in ONCOFERTILITY: FERTILITY PRESERVATION FOR CANCER SURVIVORS 180, 182-83 (Teresa K. Woodruff & Karrie Ann Snyder eds., 2007) (recognizing the importance of fertility to many cancer patients, and how psychosocial screening can alert physicians to patients' fertility preservation desires); Stephanie J. Lee et al., *American Society of Clinical Oncology Recommendations on Fertility Preservation in Cancer Patients*, 24 J. CLINICAL ONCOLOGY 2917, 2921 (2006) (noting a vast majority of cancer patients treated during their reproductive years are interested in discussing fertility preservation options). Many cancer treatments are toxic to the reproductive organs, and cancer survivors sometimes feel "incomplete" if they become infertile. Gregory Dolin et al., *Medical Hope, Legal Pitfalls: Potential Legal Issues in the Emerging Field of Oncofertility*, 49 SANTA CLARA L. REV. 673, 674 (2009).

354. Cf. Carrie Nieman et al., *Fertility Preservation and Adolescent Cancer Patients: Lessons from Adult Survivors of Childhood Cancer and Their Parents*, in ONCOFERTILITY: FERTILITY PRESERVATION FOR CANCER SURVIVORS, *supra* note 353, at 201, 208 (recounting how some cancer survivors did not remember talking to their physicians about fertility concerns).

355. Cf. Dolin et al., *supra* note 353, at 674. ("Whereas in the past fertility was not even part of the discussion when deciding on the proper treatment, now it is a top concern of many newly diagnosed cancer patients."). The University of Texas MD Anderson Cancer Center offers sexuality and fertility counseling, as well as sperm banking, as part of its Adolescent and Young Adult Program. MD Anderson Adolescent & Young Adult (AYA) Program, <http://www.mdanderson.org/patient-and-cancer-information/care-centers-and-clinics/childrens-cancer-hospital/support-programs/aya-program.html> (last visited Oct. 7, 2010). The Texas Children's Hospital Cancer Center specifically notes that psychosocial challenges of treating teenaged patients include issues of intimacy and fertility. Texas Children's Hospital, <http://www.texaschildrens.org/Parents/TipsArticles/ArticleDisplay.aspx?aid=983> (last visited Oct.

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care plan should include the patient's fertility preservation decision. Just as parents are not permitted, without good cause and court approval, to forcibly sterilize their children, it has been argued that when a parent chooses not to consent to fertility preservation, the adolescent is deprived of his or her right to procreate.<sup>356</sup> Although policy, history and precedent indicate that a minor should have full autonomy regarding fertility preservation, there is no specific case law or legislation on this issue.<sup>357</sup> This makes the ICPC the optimal forum to address these issues, as the ethics committee and hospital risk management are automatically a part of the coordinated interdisciplinary team and can be consulted should a conflict arise.<sup>358</sup>

- **Psychological Aspects of Care:** This section of the care plan documents the patient or family's need for emotional support.<sup>359</sup> This includes the previously discussed anxiety and depressive disorders, but also incorporates grief and bereavement counseling.<sup>360</sup>
- **Spiritual Aspects of Care:** Based on the information learned during the Relationship phase, the care team will be aware of the patient's and family's spiritual beliefs. The team will document any religious

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7, 2010). Semen cryopreservation is available for post-pubescent male patients. Ovarian tissue cryopreservation, where cortical tissue strips are obtained and re-implanted at the time of remission, may be an option for females depending on the type of cancer. *In vitro* follicle maturation is in the experimental phase. Cf. Evelyn E. Telfer et al., *A Two-Step Serum-Free Culture System Supports Development of Human Oocytes from Primordial Follicles in the Presence of Activin*, 23 HUM. REPRODUCTION 1151, 1155 (2008) (reporting success of growing human follicles from cortical strips); Min Xu et al., *Tissue-Engineered Follicles Produce Live, Fertile Offspring*, 12 TISSUE ENGINEERING 2739, 2739-40 (2006) (mentioning ovarian tissue cryopreservation as one option for preserving fertility).

356. Dolin et al., *supra* note 353, at 698-704 (citing Kathleen M. Boozang, *CAM for Kids*, 1 Hous. J. Health L. & Pol'y 109, 123 (2001) ("[A] court order is typically obtained before an incompetent minor is sterilized . . . .")); cf. *Michigan Protection & Advocacy Serv. v. Kirkendall*, 841 F. Supp. 796, 801 (E.D. Mich. 1993) ("[S]terilization is defined by the legislature as an extraordinary measure which is to be decided by a court and undertaken only pursuant to court order."); *In re Truesdell*, 304 S.E.2d 793, 806 (N.C. Ct. App. 1983) (recognizing that procreation is a fundamental right and delineating standards the state must meet to compel sterilization).

357. See Dolin et al., *supra* note 353, at 707-12; see also Christine Muckle, Comment, *Giving a Voice to Intersex Individuals through Hospital Ethics Committees*, 2006 Wis. L. Rev. 987, 1000-01 (2006) (noting that in sterilization cases, courts do not show parents "the same level of deference they would normally receive").

358. The issue of what to do with stored gametes/genetic material is beyond the scope of this issue. Case law suggests that courts will look to "wishes expressed by the deceased donor during the course of his life." Dolin et al., *supra* note 353, at 710; see also *id.* at 704 (citing *Hecht v. Superior Court*, 20 Cal. Rptr. 2d 275 (Ct. App. 1993)); *Estate of Kievernagel*, 166 Cal. App. 4th 1024 (Ct. App. 2008); cf. *Kurchner v. State Farm Fire & Cas. Co.*, 858 So. 2d 1220, 1221 (Fla. Dist. Ct. App. 2003) (relying on *Hecht* to conclude that frozen sperm is to be treated like personal property).

359. ICPC I, *supra* note 96, at 253.

360. *Id.*

preferences, chaplain or clergy requests, and the family's general definitions of hope, meaning, and faith.<sup>361</sup>

- **Social Aspects of Care:** The social services department and the child life department are actively involved in this domain. The plan should document sibling and parent support, the patient's goals concerning self-care and privacy, and any financial support issues the family is facing.<sup>362</sup>
- **Cultural Aspects of Care:** The family's cultural preferences and customs, learned during the Relationship phase, should be documented in the plan.<sup>363</sup> The team should encourage continued participation in cultural practices or holidays to preserve an atmosphere of normalcy.
- **Care of the Imminently Dying:** When a patient is near the end-of-life period, the plan will document symptoms, coping, anticipatory guidelines, communication, grief, and funeral arrangements.<sup>364</sup> The documentation will also include the child life team's role in end of the life care. The child life team will help families discuss the impending death with siblings, extended family, and friends.<sup>365</sup> Child life specialists also help make mementos of the child, including handprints after the child dies.<sup>366</sup> The care team at St. Jude Children's Research Hospital recommends that members attend the funeral, and that the team maintain contact with the family for thirteen months after the child's death.<sup>367</sup>
- **Ethical and Legal Aspects of Care:** Every ethics consultation and risk management involvement must be documented.<sup>368</sup> The plan will also document the withholding or withdrawing of treatment with curative intent.<sup>369</sup>
- **Educational Aspects of Care:** The plan should document when the family is presented with information on anticipatory guidelines, home health, hospice, and the dying process.<sup>370</sup> Their comprehension level should also be documented.
- **Relational Aspects of Care:** The care team should first document if the patient and family are effectively communicating emotions and grief

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361. *See id.*

362. *See id.*

363. *See id.*

364. *See id.*

365. Anne E. Kazak et al., *Evidence-Based Assessment, Intervention and Psychosocial Care in Pediatric Oncology: A Blueprint for Comprehensive Services Across Treatment*, 32 J. PEDIATRIC PSYCHOL. 1099, 1104 (2007).

366. *Id.*

367. *See* ICPC II, *supra* note 288, at 229.

368. ICPC I, *supra* note 96, at 253.

369. *See id.*

370. *See id.*

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together.<sup>371</sup> If this is not occurring, the team can provide guided therapeutic sessions to ensure opportunities for expression of love, gratitude, forgiveness, and farewell.<sup>372</sup>

- **Structure of Care:** Lastly, the team should document the utilization of pediatric center resources, care coordination plans, and discharge planning.<sup>373</sup> An essential purpose of the ICPC plan is to “integrate quality palliative care into the mainstream of medical treatment of all children suffering from chronic, life-threatening, and life-limiting illnesses, regardless of the curative intent of therapy.”<sup>374</sup> As part of the ICPC model’s care coordination, the palliative service works with the family throughout the course of illness, not just during the end-of-life period.<sup>375</sup> As a result, the family and patient will experience continuity in care during the times of crisis, such as a relapse or during the final weeks of life.<sup>376</sup> Without the ICPC approach, families and patients often report feelings of abandonment during the end-of-life period, and this complicates the grief process after the patient’s death.<sup>377</sup> Under the ICPC care coordination practice, the family will have an established relationship with the palliative service when curative efforts are finally replaced by comfort measures.<sup>378</sup> Discussions with various providers will not have to be repeated as a result of poor physician communication. The patient and family will receive information from a consistent, trusted team.<sup>379</sup>

This Note recommends one additional domain designed specifically for adolescents: The Adolescent Advanced Directive or what Weiner et al. calls *How I Wish to Be Remembered*.<sup>380</sup> An advanced care planning document is important for any terminally ill patient, and there is particular need for a document designed specifically for adolescents. Based on a study conducted by physicians and researchers at the National Institutes of Health’s Pediatric Oncology and Mental Health branches, this Note recommends that adolescent patients be provided with an advance directive pre-tailored to document the specific planning concerns of adolescents. Although over 90% of the young adults surveyed by the researchers

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371. *See id.*

372. *See id.*

373. *See id.*

374. ICPC II, *supra* note 288, at 224-29 (explaining that the ethics committee promotes care coordination and is an integral partner with the palliative care service).

375. *Id.* at 234-35.

376. *Id.* at 228.

377. *Id.* at 238-39.

378. *Id.*

379. *Id.* at 239.

380. *See generally* Lori Wiener et al., *How I Wish To Be Remembered: The Use of an Advance Care Planning Document in Adolescent and Young Adult Populations*, 11 J. PALLIATIVE MED. 1309 (2008) (discussing an adolescent’s need to share personal, emotional, and spiritual wishes).



stated that the use of a directive “could be helpful” to them, the study found that the adolescents who participated in the study were dissatisfied with the advance directive most commonly used with adult patients.<sup>381</sup> Participants cited both a lack of open-ended questions and a disproportionate focus on concerns that were of a low priority to the young adult population.<sup>382</sup> Respondents did not consider, for instance, concerns about assisted living, hospice, and medical record release to be a particularly important use of the document.<sup>383</sup> Other feedback included complaints about inaccessible language.<sup>384</sup> For example, participants disliked the phrase “health care agent,” citing it to be unclear and impersonal.<sup>385</sup> The term “chosen responsible adult” was determined the best alternative among study participants.<sup>386</sup> Additionally, the respondents wanted an open-ended section that would detail who and what they wanted around them at the end-of-life, including friends, personal items, and music.<sup>387</sup> This type of structured yet flexible document will provide an excellent addition to the ICPC’s patient-centered approach when working with terminally ill adolescents.

The ICPC Model is the best preventative measure a pediatric medical center can adopt in an effort to avert conflicts amongst patients, their families, and the health care team. However, should an end-of-life conflict prove irresolvable, this Note advocates that state legislatures enact a statutory fallback provision. The following section recommends the type of legislative language best suited to resolve an adolescent end-of-life conflict.

### *B. A Proposed Statutory Solution: Use of New Mexico’s Statute*

Section 24-7A-6.1 of the New Mexico Uniform Health-Care Decisions Act is an ideal forced exit to a conflict because of its specificity and consideration of the overall illness experience. The Act reads as follows:

A. Except as otherwise provided by law, a parent or guardian of an unemancipated minor may make that minor’s health-care decisions.

B. A parent or guardian of an unemancipated minor shall have the authority to withhold or withdraw life-sustaining treatment for the unemancipated minor, subject to the provisions of this section and the standards for surrogate decision-making for adults provided for in the Uniform Health-Care Decisions Act.<sup>388</sup>

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381. *Id.* at 1311-12.

382. *Id.* at 1312-13.

383. *Id.*

384. *Id.*

385. *Id.*

386. *Id.*

387. *Id.* at 1313.

388. The Act reads as follows:

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C. Subject to the provisions of Subsection B of this section, *if an unemancipated minor has capacity sufficient to understand the nature of that unemancipated minor's medical condition, the risks and benefits of treatment and the contemplated decision to withhold or withdraw life-sustaining treatment, that unemancipated minor shall have the authority to withhold or withdraw life-sustaining treatment.*

D. For purposes of Subsection C of this section, *a determination of the mental and emotional capacity of an unemancipated minor shall be determined by two qualified health-care professionals, one of whom shall be the unemancipated minor's primary physician and the other of whom shall be a physician that works with unemancipated minors of the minor's age in the ordinary course of that physician's health-care practice.* If the unemancipated minor lacks capacity due to mental illness or developmental disability, one of the qualified health-care professionals shall be a person whose training and expertise aid in the assessment of functional impairment.

E. If the unemancipated minor's primary physician has reason to believe that a parent or guardian of an unemancipated minor, including a non-custodial parent, has not been informed of a decision to withhold or withdraw life-sustaining treatment, the primary physician shall make reasonable efforts to determine if the uninformed parent or guardian has maintained substantial and continuous contact with the unemancipated minor and, if so, shall make reasonable efforts to notify that parent or guardian before implementing a

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A. The Uniform Health-Care Decisions Act does not affect the right of an individual to make health-care decisions while having capacity to do so.

B. An individual is presumed to have capacity to make a health-care decision, to give or revoke an advance health-care directive and to designate a surrogate.

C. Unless otherwise specified in a written advance health-care directive, a determination that an individual lacks or has recovered capacity or that another condition exists that affects an individual's instruction or the authority of an agent shall be made by two qualified health-care professionals, one of whom shall be the primary physician. If the lack of capacity is determined to exist because of mental illness or developmental disability, one of the qualified health-care professionals shall be a person whose training and expertise aid in the assessment of functional impairment.

D. An individual shall not be determined to lack capacity solely on the basis that the individual chooses not to accept the treatment recommended by a health-care provider.

E. An individual, at any time, may challenge a determination that the individual lacks capacity by a signed writing or by personally informing a health-care provider of the challenge. A health-care provider who is informed by the individual of a challenge shall promptly communicate the fact of the challenge to the supervising health-care provider and to any health-care institution at which the individual is receiving care. Such a challenge shall prevail unless otherwise ordered by the court in a proceeding brought pursuant to the provisions of [N.M. STAT. ANN. § 24-7A-14 (West 2009)].

N.M. STAT. ANN. § 24-7A-11 (West 2009).

decision.<sup>389</sup>

This is the best language for several reasons. First, an established rule is significantly easier to apply than a common law doctrine when the issue involves important “public policy and societal concerns.”<sup>390</sup> Second, the New Mexico statute is preferable because it does not automatically require judicial intervention. As evidenced by the similarly controversial realm of adolescent abortion, many courts are reluctant to hear cases that are politically and ethically charged, and therefore may handle the cases improperly or reject the case altogether.<sup>391</sup> In a recent survey of Texas courts’ preparedness to handle the judicial bypass proceeding available to adolescent’s seeking abortion, fewer than half met the statutory criteria.<sup>392</sup> These courts did not acknowledge that their office was responsible for handling the judicial bypass procedure, nor did they disclose that a minor could have an attorney appointed for her.<sup>393</sup> Some county clerks stated that their court refused to handle anything regarding abortions.<sup>394</sup> When asked, more than two judges refused to appoint the minor an attorney, which is her right under the Texas Family Code.<sup>395</sup> Several other judges are on record as saying that they personally do not believe in abortion and will not grant a waiver for a minor.<sup>396</sup>

Although the volume of adolescent medical autonomy case law is nominal when compared to abortion-related bypass procedures, this practiced avoidance is

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389. N.M. STAT. ANN. § 24-7A-6.1 (West 2009) (emphasis added).

390. *In re Rosebush*, 491 N.W.2d 633 (Mich. Ct. App. 1992) (Sawyer, J., dissenting); see also *In re Long Island Jewish Med. Ctr.*, 557 N.Y.S.2d 239, 243 (N.Y. Sup. Ct. 1990) (praising a “mature minor” doctrine); *Commonwealth v. Nixon*, 761 A.2d 1151, 1155 (Pa. 2000) (applying public policy considerations).

391. See Helena Silverstein & Leanne Speitel, “*Honey, I Have No Idea*”: Court Readiness To Handle Petitions To Waive Parental Consent for Abortion, 88 IOWA L. REV. 75 (2002).

392. *Id.* at 75-85.

393. Melissa Jacobs, *Are Courts Prepared To Handle Judicial Bypass Proceedings?*, 32 HUM. RTS. J. SEC. INDIVIDUAL RTS. & RESPONSIBILITIES 4, 5 (2005). The Texas Family Code requires a court to appoint an attorney *ad litem* for a minor if she has not retained one herself; the hearing and ruling must take place by 5:00 P.M. of the second business day following the application or the waiver will be deemed granted; the court must grant the minor’s request if it finds by a preponderance of the evidence that a “minor is mature and sufficiently well informed” to make the abortion decision independently, or that notification would not be in her best interest, or that notification “may lead to physical, sexual, or emotional abuse of the minor;” lastly, the court must protect the minor’s anonymity. TEX. FAM. CODE ANN. § 33.003(i)(k) (Vernon 2010).

394. *Id.* at 5.

395. *Id.* The following information was also reported: two courts stated that a guardian *ad litem* would be appointed for the fetus; one stated that the petition would not be granted unless the mother’s health was in imminent danger (although the statute creates a separate exception for emergencies); one court erroneously stated that the father of the baby had to be notified and given twenty days to respond; and multiple courts believed that minors had to prove indigence to qualify for a court-appointed attorney, even though the statute does not require a showing of financial need. *Id.*

396. *Id.*

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nevertheless documented in published opinions. In one case, the court refused to acknowledge the mature minor doctrine, instead deferring the task of "taking a hard look at the mature minor doctrine for either statutory or decisional law" to the state legislature.<sup>397</sup>

The cogency and clarity of the statutory language of the New Mexico law should be the model for other state legislatures. The New Mexico statute, unique in its specificity, provides a roadmap for physicians, medical centers, and families. The statute first sets forth a rule stating that an unemancipated minor shall have the authority to withhold or withdraw life-sustaining treatment if he or she has sufficient capacity to understand the illness, the risks and benefits of treatment, and the likely consequences of the decision.<sup>398</sup> A provision of this nature is not exclusive to the law of New Mexico; other states, including Arkansas, have provisions with similar language.<sup>399</sup> However, the New Mexico legislature's direction on how to determine said capacity is what makes this statute truly accessible to patients, families, and care teams in times of crisis.<sup>400</sup> The statute provides that emotional capacity be determined by two physicians, one of whom is the primary physician.<sup>401</sup> Because this statute is recommended as a fallback provision to the ICPC model, the treating physician will have the benefit of thoroughly understanding a patient's maturity and comprehension of prognosis and consequences. The physician will also be aware of the decisive factors of the choice to withdraw or withhold LSMT. A determination of mental and emotional capacity must also be made by a second physician that works with similarly situated minors in the ordinary course of his practice. This incorporates necessary checks and balances that ensure the treating physician is not overburdened with this responsibility.<sup>402</sup>

Combining the ICPC Model and the statutory fallback provision is a reliable and responsible solution to the problem of adolescent patient autonomy. It affords critically ill adolescents the autonomy many of them desire and deserve. Perhaps most importantly, the combination preserves the family integrity, enhances the patient's quality of life, and empowers patients to choose how they wish to be remembered.

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397. *In re Long Island Jewish Med. Ctr.*, 557 N.Y.S.2d 239, 243 (N.Y. Sup. Ct. 1990) (granting the relief requested because it found that the patient was not a mature minor under the circumstances, although there was much merit to the mature minor doctrine itself). The court recommended that the NY Legislature or the appellate courts take a "hard look at the mature minor doctrine and make it either statutory or decisional law." *Id.*

398. *See* N.M. STAT. ANN. § 24-7A-6.1 (West 2009).

399. *See, e.g.*, ARK. CODE ANN. § 20-9-602(7) (West 2009) (stating that any unemancipated minor of sufficient intelligence to understand and appreciate the consequences of the proposed surgical or medical treatment or procedures may make medical decisions for himself or herself).

400. *See id.* The extremely broad Arkansas statute gives no guidance on how to determine "sufficient intelligence to understand and appreciate the consequences of the proposed surgical or medical treatment or procedures."

401. N.M. STAT. ANN. § 24-7A-6.1 (West 2009).

402. *Id.*

## CONCLUSION

To cure sometimes, to relieve often, to comfort always – this is our work.<sup>403</sup>

- *Motto of the Palliative Care Team at St. Jude Children's Research Hospital.*

Originally developed for patients undergoing stem cell transplantation, the ICPC is ideal for patients with any illness associated with significant suffering, a high incidence of morbidity and mortality, and the need to make frequent difficult decisions in an ethical manner.<sup>404</sup> The integration of the ICPC Model with the statutory fallback provision will support teens through the no man's land of adolescent critical illness. It ensures that the adolescent patient's relationship with his or her family does not become collateral damage of the overall illness experience.

Tyler Alfriend and Michael Miller are not the exception; they are the rule. As previously noted, the family dynamic is changed when a teen is diagnosed with a critical illness, as the teen often assumes the role of emotional caregiver to his or her parents.<sup>405</sup> Establishing an integrated approach to care first requires an acknowledgement that the current assumptions regarding adolescent maturation are outdated and inaccurate. Each critically ill adolescent responds differently to illness, and the ICPC model allows the care team to see beyond the patient's age and assess maturity on an individual basis. In the case of Michael Miller, his oncologist admitted worrying that he would begin skateboarding as soon as he would leave the hospital.<sup>406</sup> Despite this concern, his care team looked beyond his love of ollies and kickflips, recognizing and respecting his maturity and positive attitude. "Michael was a joy to take care of," his physician commented. "He was well aware of everything he was missing at home . . . but he went through everything with a smile."<sup>407</sup> Understanding the personality of each patient builds a stronger physician-patient relationship, and allows the patient and family to rise above emotional set-backs.

As illustrated above, patient-tailored care will ease the heartbreak of illness, reduce conflict, and ensure that the family feels as though the patient had the best possible life and death. This Note demonstrates how legal and medical professionals can work together to establish a fluid, individualized approach to adolescent medical autonomy. The analysis proves the efficacy of the model in diverse clinical settings and that, when implemented, it will improve the lives of all pediatric patients facing life-threatening conditions and challenges. The three phases of the model are a comprehensive yet compassionate approach to advance care planning. The Relationship phase builds a center of trust between the

403. ICPC II, *supra* note 288, at 223.

404. *Cf.* ICPC I, *supra* note 96, at 246-47.

405. *Id.* ICPC I, *supra* note 96, at 246.

406. Roll Model, *supra* note 4.

407. Roll Model, *supra* note 4.

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patient, family, and physician. Each party has the responsibility to share relevant information with each other and to ensure that the patient's care team can generate a comprehensive needs assessment. The Negotiation phase allows both the patient and the parents an opportunity to voice their concerns regarding the care plan. During this phase, the team can bring in any specialist, including an ethicist, to assist in resolving any discordant step in the process. Finally, the plan's implementation ensures that the totality of the patient's needs is met by his or her care team. Through these processes, the care team will identify disagreements before they occur and attempt to mitigate and resolve any conflicts. Should a problem persist, the statutory component of the combination model permits the physician to fulfill his ethical obligations to the adolescent patient without the fear of a public judicial intervention.

Eliminating the "no man's land" of adolescent critical illness requires reducing emotional harm and bridging the gap between childhood and adulthood. This Note argues that the implementation of the ICPC protocol will enhance the adolescent patient's quality of life, reduce overall family stress, and offer an alternative to courtroom adjudication. Because the benefits of the ICPC model are so extensive, the ICPC structure should be implemented at any pediatric care center that strives to provide patient-centered care.

